

What is suffering?

“Suffering is a specific state of severe distress induced by the loss of integrity, intactness, cohesiveness, or wholeness of the person, or by a threat that the person believes will result in the dissolution of his or her integrity.” (Cassell, 1995).

Suffering can help define the idea of person. If persons are created by their thoughts and beliefs, by their past, their present, and a sense of their future, as well as by an understanding that there is some level of stability in the world, then suffering can potentially be experienced whenever there are any changes in the person’s physical, emotional, social, spiritual or political environment. As defined by Gregory and English “suffering is a profoundly subjective, holistic experience that is constituted in the biography and lived world experiences of patients.” Suffering is not a diagnosis, rather it is an aspect of conscious human existence.

“one can have pain and not suffer”

For many, suffering may be seen as the secondary reaction to the experience of pain. The primary reaction is the sensation of the pain itself, while the suffering is the individual’s response to that experience. Suffering therefore, is derived from the individual’s evaluation of the significance or meaning of the pain, distress, or other negative experience. In the relationship between physical pain and suffering, people often report suffering when the pain they experience makes them feel out of control. This lack of control may be felt when they don’t know the source of their pain, when their pain cannot be

controlled or when there doesn’t seem to be any purpose for the pain experience. The pain is seen as a threat to their continued existence and to the control that they have over their life – their integrity as persons. One can have pain and not suffer. Pain can obviously be unpleasant, but if the person experiencing the pain understands why they have the pain and then perceives it as non-threatening, the pain itself may not cause suffering.

Suffering can be caused by many things. Woodruff’s analysis of suffering points to several causes – pain, physical symptoms, psychological problems, social difficulties, cultural factors and spiritual concerns. Many of the contributing factors to suffering

“Staff of the Centre with Archbishop Pell who joined the Staff and Board of Management for an informal luncheon meeting”

From left to right:

Margaret Casey, Tracey Phelan, Archbishop George Pell, Deirdre Fetherstonhaugh, Fr Norman Ford and Anna Stokes.

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are interrelated, so that help given to someone to relieve suffering which manifests itself in one way, must also take into account the other possible causes of suffering. Suffering is not always confined to physical symptoms. People can suffer not only from a disease but from the treatment of that disease – a mastectomy may be the treatment of choice for carcinoma of the breast, but in losing part of the body in an effort to save the whole body the patient may suffer a sense of loss and mutilation, the degree of which cannot be diminished because of the overall ‘good’ in the goal of treatment.

Suffering is a state which in some situations can be tolerated if there is a purpose, if there is a good that can be achieved through the experience. Childbirth is such an example. For those with unrelenting terminal or chronic diseases, where each day brings a further loss in bodily functions, there may not seem to be any purpose to their suffering. Suffering may be tolerated if it is finite because the time of suffering has an end and the person looks to the future when they will suffer no more. Death itself, may be that time without suffering.

What can Affect Suffering and who can Experience it?

Personality and character traits as well as past life experiences can affect suffering. Cultural and social background can also contribute. They can define attitudes to the sick and dying. They can determine the level of acceptance for those with infectious diseases or the amount of tolerance for odours and excreta (it is acceptable for a baby or a small child to be incontinent and they suffer no embarrassment for being so, whilst it is not so well tolerated in adults and for them can be a source of humiliation and shame). For a person to live successfully with a colostomy or ileostomy, being in control of the stoma, the bags and the odour is very important. Cultural

background and socialisation can also determine how males and females react in certain situations. The loss of a definitive role cannot be overlooked in the experience of suffering. A sick person may be unable to fulfil the role of parent or spouse – lying incapacitated and helpless, suffering because they are not able to even tend to the physical needs of their loved ones. All these things can affect the behaviour of the sick towards themselves and of others toward the sick person. The impact of being a witness to suf-

“only someone who is conscious can suffer”

fering and being unable to respond appropriately to alleviate or at least minimise it, creates suffering in that witness, whether they be family, friend or health care worker. This in turn can add to the suffering of the patient. For the caring parent who can only look on helplessly as their terminally or chronically ill child lies disabled and defenceless in a bed, their suffering can be unbearable. They feel useless as they are unable to fulfil their parenting role of protector and corrector of wrongs.

Admiraal has the following to say about suffering and who can experience it – “Only someone who is conscious and capable of deliberative retrospective and prospective contemplation can suffer. The person who suffers compares, weighs, and evaluates life in the past and in the future. Suffering, therefore, also includes grief, depression, concern and anxiety. But, fortunately, it may also include the essentially human characteristics of hope, acquiescence and acceptance. Thus, the suffering of a human being is strictly individual and is determined by the psychological tensions and inner resources of the individual in enduring the condition.”

If suffering involves persons and threats to their own sense of intactness or wholeness, it requires a sense of identity, of the past, and of the fu-

ture. The capacity to appreciate these things must be present for suffering to occur. It could appear then that the permanently unconscious cannot suffer, but pain could not in principle be excluded.

One cannot always anticipate what a particular person will describe as a source of suffering unless you ask them. In the case of the patient who cannot communicate, is permanently unconscious or whose cognitive functions are impaired, the suffering, if it is indeed being experienced, cannot be expressed and can only be perceived by the carers or the relatives. In this instance, the social and cultural conditioning of the onlooker and their own past life experiences cannot be ignored, as it is *their* perception of “what is suffering?” and “when it can appropriately be experienced” that causes the reaction to their loved one’s present state of being.

The Ethical Duty in Regard to Suffering

There is an ethical duty not to inflict pain and suffering beyond what is necessary for accurate diagnosis and warranted treatment (with the consent of the competent patient). Then, there is the duty to do all that can be done within the limits of current medical knowledge and available resources to relieve all the pain and suffering that can be palliated. As noted by Cassell, it can be the failure of health professionals to understand the nature of suffering which results in medical intervention that (though technically adequate) not only fails to relieve suffering, but actually becomes a source of suffering itself. Reliance on a dialysis machine with the associated strict regimen of drugs, diet and fluid restriction for life may be the medically indicated course of action but it may cause untold suffering to the patient. Total dependence on a machine and loss of autonomy and freedom may for the patient be a fate worse than death.

The suffering which is involved in

the intensely, negative feelings of loneliness, loss of dignity, guilt, depression, anxiety, fear, humiliation, alienation, uncertainty, monotony, helplessness etc. is as much in need of relief as is physical pain. Those who deal with the sick have just as great a moral obligation to help patients cope with this type of suffering as they have to relieve localised bodily discomforts.

If we accept that we have an obliga-

“only the individual knows his suffering directly”

tion to help relieve the unnecessary suffering of others, we must be able to ascertain with reasonable accuracy that they are suffering and also the type and the extent of their suffering. Only the individual knows his suffering directly. In the case of the incompetent or the person who is unable to communicate coherently, the problem lies in the assessment of any suffering. Relatives and carers of a chronically ill, incompetent patient may identify changes in so-called “normal” behaviour as evidence of pain, discomfort or suffering – the difficult question then is to determine what is causing this change in behaviour, whether the origin of this pain, discomfort or suffering can be specifically located and whether anything can be done to alleviate it. It is our inability to know with certainty whether, or why, someone is suffering, and our inability to then identify with the sufferer which can create difficulties for treatment options. In the case of the person who is unable to express whether they are suffering it is often those people around them who are really suffering. These onlookers (for want of a better term) may have had close, mutual, interactive relationships with the person in the past, and are faced with the prospect of not being able to maintain that relationship in its previous form any more. This is not to say that the relationship has ended just because it appears one sided.

It may also be that the onlookers are unable to accept the person’s present

condition – of mutilation, disablement, helplessness etc. As Cassell states “people suffer from what they have lost of themselves in relation to the world of objects, events and relationships.” Therefore, when it comes to the incompetent patient it is the carers and relatives who have this sense of loss for what was and will *never* be again. It is they who have a memory of what this person was and of the potential that they may once have had. The person that they love, is reduced to a state of paralysis, uncontrolled spastic movements, helplessness, incontinence, unable to relate in any way with the environment and the people around them. Perhaps *they themselves* feel that they could not tolerate being in such a situation. They then project their perception of suffering to mean that their relative or patient must be suffering, regardless of whether they actually have the cognitive ability to contemplate their current situation either prospectively or retrospectively.

The relief of suffering is multifaceted. It can be sought firstly, by recognising that it is being experienced, secondly, by seeking the cause and meaning of the suffering and thirdly by locating the person and their suffering in a far bigger picture.

Conclusion

Suffering is a very difficult concept to define. This is due mainly to its individual nature but at least for those who are able to communicate their suffering, something can be done – in the case of health care this may mean the withdrawal of overly burdensome treatment. The worst aspect of suffering is not the pain which can be relieved (or relief at least attempted) – but the helplessness, uselessness and the seeming loss of control which is embodied in the suffering. What may be seen as burdensome treatment by onlookers (family, friends and carers) may not be so for the patient. Perhaps then, it is the family and the carers who need to be relieved of their suffering through compassion, listening and

understanding.

The relief of suffering is of pressing importance in the last part of this century and into the next because of the increasing prevalence of chronic disease in the community and the changing demographic composition of our society where people are living longer. Very sick people are being kept alive in chronic states of ill health. Chronic disease has the potential to cause great suffering as it threatens a person’s sense of future. It poses an actual or perceived threat to their well being and their ability to accomplish previously important purposes. It endangers their integrity or their sense of wholeness which in turn threatens their existence as they now know it.

We cannot ignore the increasing specialisation in medicine and other health professions which dissect the person into parts or body systems. Somewhere amongst all those parts is a person and we must ensure that it is their total wellbeing which is of the utmost importance. We must support whole person care in the hope that we may be able to alleviate suffering. Physicians and other health care workers have to be careful not to make assumptions about whether a person is suffering based on their objective knowledge of a disease, its anatomy and physiology and its likely course rather than on an understanding of the disease in the person. As William Osler said (quoted by Balfour Mount) “It is as important to know the person who has the disease than to know the disease the person has.” †

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Sources

Admiraal, Pieter. “Voluntary Euthanasia: The Dutch Way”, *Death, Dying and The Law*. Ed. Sheila A M McLean Dartmouth Publishing Company, 1996, 116.

Cassell, Eric J. “Pain and Suffering.” *Encyclopedia of Bioethics* New York: Simon & Schuster Vol 4

(1995), 1897 - 1905.

Cassell, Eric J. "The Nature of Suffering and the Goals of Medicine." *New England Journal of Medicine* 306:11 (1982), 639 - 645.

Edwards, Rem B. "Pain and the Ethics of Pain Management." *Social*

Science & Medicine 18:6 (1984), 515 - 523.

Gregory, David and English, John. "The Myth of Control: Suffering in Palliative Care." *Journal of Palliative Care* 10:2 (1994), 18 - 23.

Mount, Balfour. "Whole person

care: Beyond psychosocial and physical needs." *The American Journal of Hospice & Palliative Care* Jan/Feb (1993), 30.

Woodruff, Roger. *Palliative Medicine*, Melbourne: Asperula Pty Ltd, 1996.

From the Director

I would like to thank those who have shown confidence in our **Bulletin** by renewing their subscriptions. I would like to invite subscribers to suggest to other interested persons to take out a subscription to our **Bulletin**. Our staff are often invited to conduct in-services for hospital staff, clergy, teachers and senior secondary students. Our staff is able to handle just about any topic related to health ethics. We are more than willing to respond to invitations to help out in this way wherever we can.

Recently we made a written and oral submission on health aspects to the Commonwealth Parliament's *Inquiry into the Status of the United Nations Convention on the Rights of the Child*. Our submission was based on our belief in the dignity of the child, respect for human life from conception to natural death and the due provision of health services to all regardless of one's stage of life, development or condition. Children have a right to community assistance to achieve bodily well-being and to have access to appropriate health services. More specifically we touched on the need for legislative action to protect the rights of the child under the following headings: reproductive technology, financial assistance to single income families, abortion and culture and the media.

The Human Genome Organisation (HUGO) is responsible for the multi-billion dollar **Human Genome Project** which involves the collaboration of scientists from many nations. It is well ahead of its schedule in mapping up to 100,000 genes located along the

46 chromosomes of each human individual. The genetic information that will become available on the completion of this project early next century will increase enormously our capacity to detect and predict genetic malformations and diseases, including late onset diseases like Huntington's chorea. HUGO has its own Ethics Committee to consider all the ethical, social and legal aspects and implications relevant to this project and its likely findings.

The United Nations Educational, Scientific and Cultural Organisation (UNESCO) also has a Committee of Governmental Experts who have prepared a *Draft Universal Declaration on the Human Genome and Human Rights* in the light of the United Nations earlier Universal Declaration of Human Rights (1948) and a host of subsequent relevant UN Declarations, Covenants and Treaties. The first article in the present draft states: "The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity." This implies that the human genome should be adequately protected from harm and that scientific knowledge of the human genome should be accessible to all interested persons.

Other articles stress the importance of respecting the dignity and rights of all regardless of their genetic characteristics. Individuals cannot be reduced to their genetic characteristics and should all be respected in their uniqueness and diversity. The fol-

lowing important ethical principles are also enshrined in the draft: "Article 4: The human genome in its natural state shall not give rise to financial gains." Presumably this would allow the patenting of a gene sequence for the making of pharmaceutical products. "Article 6: No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity."

Strict conditions for research or its applications concerning the human genome are laid down in the context of ethical regard for universal human solidarity, informed and free consent, confidentiality and human freedom. The reproductive cloning of human beings and research on the human genome involving undue risks of harm or abuse are not to be permitted. Article 19 encourages international co-operation, the sharing of the benefits of research with developing countries and "the free exchange of scientific knowledge and information in the areas of biology, genetics and medicine."

UNESCO is to be commended for preparing this Declaration for the benefit and protection of humankind and the family of nations. I hope that Australia takes the appropriate legislative action once the Declaration is approved by UNESCO. It is not good enough to rely on non-binding guidelines of the National Health and Medical Research Council.

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The Role of Pastoral Care in Treatment Decisions at the End of Life

Most patients in hospital have a religious affiliation – e.g. Christian, Jewish, Muslim or Hindu. Others again do not adhere to any particular religious faith. There is a need, however, to offer adequate pastoral care to all patients. This article discusses how pastoral carers may be of assistance to patients in hospital.

Introduction

The Christian community recognises that there are particular times in life when people search for understanding and meaning. The experience of illness and death impacts on the person's physical, intellectual, cognitive, emotional, social and spiritual well-being. For Christians, pastoral care is a specific ministry. "The vocation and right of Christians to do this ministry are grounded in their baptism, through which they are incorporated with others into the one body of the risen Christ and share his life. The ultimate source, origin, model and measure of their ministry is the person of Jesus." *

The pastoral carer "enters into a relationship aimed at helping a person use their spiritual resources and/or tradition in their work of unifying and integrating their experiences of illness, suffering and death." * The task of the pastoral carer is not to impose answers or interpretations so much as to assist in uncovering them. A pastoral relationship thus involves a commitment to another person in their search for truth.

The pastoral carer places their pastoral and theological insight at the service of another in order to discern from within the encounter the experiences which have formed, shaped and sustained the person during their life. The pastoral carer together with the individual and/or family identify the means that have enabled the person to transcend the previous struggles and crises of their lives. In this they seek to be understood and to understand what is saving knowledge for them, and how they can use this knowledge in their present situation.

The pastoral care relationship is fundamental to the delivery of pastoral care. It is through this relationship that the pastoral carer ministers *to*, and is able to place their knowledge and experience at the disposal of, those they serve. The principles, values and dignity, justice and forgiveness, embodied in this relationship give witness to the gospel. For this reason, the code of ethics is chiefly a tool, essential for reflection on the pastoral care relationship.

Pastoral Care Service

The role of the pastoral carer is to provide for the spiritual and emotional well-being of the person. This often begins with a religious focus, especially during crisis, grief and loss. This listening, supporting, reconciling and healing through counselling, begins with the patient, extends to families and staff, and is involved on an interfaith and multi-cultural basis.

"a pastoral relationship involves a commitment to another person in their search for truth"

Spiritual care forms part of the circle of total holistic care of the person. This approach has been developed by Peter Henriot and Joe Holland. I will draw on this model later to consider pastoral aspects of care when a decision to withdraw treatment is imminent.

The *Pastoral Care Circle* begins from the experience through to immersion or entering into the experience, companioning those concerned pastorally – reflectively listening to the lived experience, to the feelings they are experiencing, to the fears, anxieties and hopes, and to how each person is responding. The re-

sponse will be unique for each person.

The second phase of reflection enables people to express their fears, anxieties and hopes and to look at the broader picture and to start drawing connections. It also provides the opportunity for dialogue. In simple terms, because of the experience of immersion, the openness of one's personal history and experience in relation to reality, a new awareness may emerge and be a foundation for action. Inattentiveness to this reality of new awakening is likely to end with truth being the victim. The main priority is to keep the process and the experience of the patient, family and staff honest and pertinent.

The third moment is theological reflection. This is an effort to understand more broadly and deeply the experience of dying. It is also a time of discovery about something that is not new, in the light of living faith, scripture and the resources of the belief system and of the faith traditions of all involved. The word of God raises new questions, suggests new insights and opens up new responses. It helps us to listen actively and attentively – to feel the pain, to interpret peoples' language, their expressions and to be there *for* them, *with* them as people, not just their labels, illness or condition.

The fourth moment in the circle is crucial and involves planning – pastoral planning. It involves working through what will give quality and meaning for the patient, and how and in what way the family will require care and support. The next step is coping with the decision making, the dying time and the time after death, and ensuring quality

support in the mourning and bereavement time. In the light of the experience analysed and reflected upon by individuals and by the community, how is this response designed in order to be most effective in the short and the long term? The caring is on a continuum and the pastoral circle continues without conclusion. Each approach does not simply retrace old steps but breaks new ground and enables the healing to continue and be life giving for all, in a spirit of hope.

The continuum of care comes full circle in creating an environment of love and comfort rather than of fear and strangeness. It enables the patient and family to focus on relationships that give life meaning. The pastoral carer fosters relationships by helping families and patients to clarify the needs and challenges they face. These include their interpersonal needs, their feelings of abandonment, their goals for the time remaining, their needs for affection and intimacy, their understanding of the myriad of feelings that surface as well as the myths about how it should be. When people feel realistically and genuinely supported they are helped greatly in coping with fear and uncertainty by focusing on the physical – that is, dealing with the reality of the disease. By focusing on the personal, the support given through pastoral care enables patients and their families to cope with disappointment, loss of control and the loss of relationships. It also allows them to deal with personal and interpersonal relationships and to cope with ultimate meaning beyond acceptance of death.

Focus on the Spiritual Dimension is Important

- The meaning and purpose of life.
- The meaning of suffering and death.
- Personal beliefs about God, or some higher being.
- The place of God in one's life.
- The here after.
- Forms of religious expression.

- One's religious belief/faith system.

Pastoral Care Within the Pain

The following case study illustrates the role of pastoral care in treatment decisions at the end of a person's life.

Peter was a 25 year old man who was admitted to ICU (Intensive Care Unit) following a drug overdose. He was a very strong, fit young man. A recreational drug user, Peter was found several hours after losing consciousness. He was admitted to ICU and placed on life support. His parents, family, and friends hovered around him for days. We prayed together, blessed him with a circle of love and care, and encouraged him through words and silence. Peter received excellent nursing and medical care and his family were kept informed on a regular basis regarding his medical status and his prognosis.

In a situation such as Peter's the flow of accurate information and space for questions and discussion is vital for family and friends. Peter's prognosis was poor and after several days it appeared that his condition was irreversible and the decision to withdraw treatment was imminent.

In the light of the *Pastoral Care Circle*, the journey of pastoral care for all concerned commenced with Peter's admission to ICU. My pastoral ministry meant entering into the experience – immersion – seeking to understand through reflective listening and caring presence with Peter's family and friends, enabling them to express their words, feelings, shock, dismay, fears and grief. Through the art of pastoral companionship, of listening presence, silence and prayer, the family were able to move into the story. Peter's story, their stories of relationship with him, their conflicts, their searching through the *WHY*, their attempt to clear their heads and minds allowed more questions to emerge. Peter's parents and family, needed support to help them

access their own inner resources of strength and faith which could free and liberate them. They needed to encircle Peter with loving energy and sustained prayer – to speak into his ear, to encourage him and remind him that he was loved and precious. The family struggled with guilt, regret for not having picked up cues which indicated personal problems and depression. As a pastoral carer, I listened actively and empathically allowing expression.

The third moment, theological reflection, enables people to face rather than avoid suffering. They become more open and trustful than rigid and prescriptive in attitude. They are encouraged to transcend the immediate, to focus on the quality rather than the quantity of Peter's life and their relationship with him. They are supported in their affirmation of the value of life in the face of death. Memories are the basis of this perception which led to simple personal hopes and prayer related to Peter's living and dying.

The fourth moment in the Pastoral Circle is about pastoral planning. How could Peter, his family, friends and the staff caring for Peter be sustained both for the short and the long term? We faced the family conference when the medical and nursing staff informed and consulted with the family regarding withdrawal of life support. Clear truthful information was conveyed and pastoral support enabled questions to be expressed as people often have difficulty digesting clinical information when they are stressed.

Peter's parents agreed that treatment should be withdrawn. They wanted to be with him to support him. I also stayed to support them. As a group we encircled Peter and prayed. He was blessed and anointed and his family farewelled him. His parents held him as the ventilator was removed. They stayed with him for as long as they needed. When they were ready, we discussed funeral arrangements and contact was made

with the relevant resource people to support them in all aspects. On going contact was assured in person, by phone and by Bereavement Outreach.

Medical and nursing staff are given support and time for caring of themselves and debriefing in such situations. We are all confronted with our own grief and responses. In the face of death we encounter our own pain, our mortality, our faith, and our life values. The pastoral carer especially, needs to be supported and sustained in their ministry through professional supervision and mentoring.

The ways to express pastoral care are countless. There are words, prayers, blessings, the gentle touch and the holding of hands. There is

cleansing and feeding, listening, silence, and presence. All of these forms of care are ways of expressing our faith that those we care for are precious and loved in God's eyes. Dying is not a sweet, sentimental event, it is a great struggle – the struggle to surrender our lives completely. This is not an obvious human response and often causes much anguish in dying people.

Dying and death often bring fear. Still, the experience of dying and caring for the dying can become the deepest experience of faith, hope and love. We can share this through being vigilant about the impact the experience has on those involved, and strive to deal with the complexity that the experience brings to our own life, ignited as it is by the circle of contact between us all.

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Denise Spencer

Sources

* St. Vincent's Hospital. *Code of Ethics for Pastoral Care Chaplains in Health Care Settings*.

Holland, Joe. Henriot, Peter S. & Maryknoll, J. *Social Analysis – Linking Faith and Justice*. New York, 1983.

Nouwen, Henri J.M. *Our Greatest Gift. A Meditation on Dying and Caring*. Hodder and Stoughton, 1994.

Rockers, Thomas H. & Hoagland, Barbara. "Full Circle-Continuum of Care." *Health Progress* 1994, Sept.

Informed Consent – The Challenge

Informed consent requires more than information disclosure. This article discusses what else informed consent requires. For informed consent to be of value both healthcare professionals and patients need to be responsible for decision making.

In the last edition of the Bulletin I discussed the standard of information disclosure that is ethically required of health professionals when gaining patients' informed consent. The personalised standard of information disclosure which I recommended, is very demanding of healthcare professionals. Unfortunately even when this stringent standard of disclosure is met or exceeded, informed consent is not necessarily guaranteed. There are several other hurdles which must be crossed in order to gain informed consent. It is these remaining challenges which this article will focus on.

Two Models of Informed Consent

Informed consent is too often thought of as the written consent form signed by patients in the presence of healthcare professionals prior to commencing treatment. The idea that consent involves a single

decision, or a set of discrete decisions following short conversations, is sometimes referred to as the 'event model' of consent. This model of informed consent can sometimes fulfil the minimal legal requirements of consent. However, if information is lacking, it falls short of even these. It also fails to meet the important goal of informed consent, that of educating patients so they can have meaningful participation in the decision making process.

The alternative, more favourable, approach to informed consent is the 'process model'. This model meets legal requirements while coming far closer to the ethical demands of informed consent. The process model attempts to combine healthcare professionals sharing information with their patients over several consultations with the patient sharing information about their values, priorities and circumstances. Consent in this model is central to an ongoing dialogue between the healthcare profes-

sional and the patient. As a result, informed consent is not necessarily a single response to a direct question. Informed consent is an awareness of what the treatment entails, why it is happening as well as being a part of all decisions regarding treatment. Sometimes the decision which requires informed consent may be simply to continue with the current treatment. The process model of consent should guarantee that the resulting therapy is the optimal treatment for the patient.

Four Elements of Informed Consent

Informed consent is often broken down into four key elements. It is the first element, information disclosure by health professionals, which enables the second important element, patient understanding to be accomplished. Also necessary for informed consent is voluntariness on the part of the patient: in other words the patient's decision should

be free from coercion. The final element of informed consent is perhaps the most obvious: the patient must

“necessary for informed consent”

actually consent to a treatment. If all four elements are successfully accomplished, patients’ informed consent will be achieved and it will have meaning and importance.

Competency and Understanding

The second element, ensuring that patients understand information, is affected by both the information disclosure of healthcare professionals as well as the competency of the patient. The patient’s ability to understand and reason effectively, is essential in the decision making process. As a result, patient competency in medical decision making is an important issue. Competency also impacts on the freedom of a patient to make their own medical decisions. A competent person is generally understood to be someone who is of ‘sound’ mind. Although competency has no fixed age, the judgement of competency is at the discretion of the doctor; it is usually around sixteen years of age. Patients of any age can be at one time or another incompetent, either permanently or for a short period of time. While young children are generally accepted as incompetent when it comes to medical decision making, incompetent adults are not so easily identified. The most obvious example of an incompetent adult is the unconscious patient. Such cases require a proxy decision maker. This may be either a previously appointed agent, a family member or a healthcare professional. The most difficult class of incompetent patients are those conscious patients who are judged by healthcare professionals to be incompetent. As a result they are unable to give their consent. When seeking informed consent this is the most confusing class of incompetent patients.

Competency and Risk

If a patient agrees to a risky procedure which offers little hope of improvement their ability to make rational decisions may be brought into question. This may be the case even if the patient is fully informed, has received all the relevant information from the healthcare team, has understood the information and has made a completely voluntary decision. However, healthcare professionals may still question whether or not the patient is competent enough to give their informed consent. In cases where a patient chooses an option that a healthcare professional does not recommend, or even does not condone, the patient may be classed as incompetent, and therefore no longer capable of giving their informed consent. The circularity of this classification is a concern. Patients whose decisions conflict with what others think is in their best interests are not necessarily incompetent. Competent patients, influenced by a variety of factors associated with ill health, may not choose the options that others think they should. Projecting the decisions that we think we would make for ourselves in a given set of circumstances on to others, who are actually in those circumstances, is not an appropriate way of evaluating a patient’s ability to give consent.

When Opinions Differ

It must be remembered that when seeking patients’ informed consent the treatment in question can be very risky, possibly life altering or even potentially life saving. Patients, who receive full information and are in a position to make a decision may still be influenced by other factors. These factors cannot always be removed from the decision making process; nor should they always be. Patients who receive a poor prognosis and are fearful of what lies ahead will be influenced in their decision making by these important factors. A fear of death can lead patients to make decisions regarding extremely risky and experimental treatments

which have uncertain prospects of success, that others, who are not dying, might classify as irrational. A fear of death is understandable and not necessarily irrational. A patient who decides to take a chance with a new experimental therapy may be both rational and competent. Healthcare professionals must remember that informed consent is valued because it respects patient autonomy and part of respecting a person’s autonomy is allowing them to make their own medical decisions, even if those decisions might be ‘mistakes’. Other factors which can influence a person’s decision making include the experience or fear of pain, the healthcare professionals’ attitudes towards treatments and pressure exerted by family members. It seems reasonable that someone who is experiencing extreme pain would agree to try nearly anything in

“outside influences affect nearly all our decisions”

an attempt to have it relieved. Outside influences affect nearly all our decisions and giving consent to medical treatment should not be any different.

Healthcare professionals are sometimes of the belief that they can make the ‘best’ decisions on behalf of their patients. They need to realise that they cannot deduce scientifically what is the best medical treatment for a particular patient just from the medical facts. Healthcare professionals are not always aware of what else is important to a particular patient. What looks statistically as the most promising treatment option may place at low risk something that is highly valued by the patient. If a patient values something enough, their sight for instance, and a procedure which can fully restore vision in a failing eye carries with it an extremely low risk of losing sight in both eyes, the patient may choose not to have the procedure because it risks what they value most. What appears medically as the best option for the patient is not. Healthcare

professionals, even after disclosing all relevant information, may still be uneasy with a patient's decision. Patients may not have the medical understanding of a healthcare professional but this lack of understanding or lack of information does not mean that they are not entitled to make their own medical decisions. Often people do not have a complete understanding or full information when making similarly important life decisions such as what career to pursue. Even if healthcare professionals disagree with a patient's decision, autonomy demands that they respect it none the less. After all, it is the patient's health and it is the patient that should be making the informed choices.

When to Seek Consent

Consent should be sought when any treatment is being considered. Informed consent is not only an issue that relates to experimental therapies. It should be central to the ongoing practice of everyday medicine. Patients should receive information about all facets of their care including prescription and over-the-counter medication. Patients should be made aware of all side effects, risks and contra-indicators of a prescribed drug. It is important that patients who understand the effects of a drug or treatment and consent are careful not to misuse the treatment or to participate in behaviours that are contra-indicated. For example some drugs should not be used in combination with one another or during pregnancy.

Consent that involves agreeing to invasive treatment such as surgery,

or commencing treatment such as chemotherapy, should not be left to just prior to the procedure. Asking a patient who is already admitted to the hospital, prepared for theatre, and lying on a trolley is not really giving the patient the opportunity to make a decision. Upon being admitted to the hospital, in cases other than emergency admissions, the patient often has already decided to receive the treatment. However, asking patients just prior to commencing treatment, while not sufficient for informed consent, may still be useful because it allows patients the opportunity to express their understandable fears or ask any remaining questions. It is important to note that a patient who is admitted to hospital and consents to certain diagnostic tests should be informed of the results, and give their consent before entering the next stage of treatment.

Patients may not Wish to be Involved in Decision Making

After all this discussion about the value and importance of gaining informed consent there remains a group of patients who for a variety of reasons may not wish to be involved in the decision making process. There is no reason to force such patients to be involved in decisions if they do not want to be. However, unless health professionals ask, they cannot know how involved a patient wants to be. Even if patients do not wish to be involved in the actual decision making they might still want as much information about their disease as the health care team can provide. Information helps patients un-

derstand what is happening to them, comply with treatment and make appropriate changes to other aspects of their life. Not wanting to make decisions should not be equated with not caring about one's health. Some patients may be happy to place the decisions in the hands of professionals but still be interested in the treatment they are receiving, and why.

The increasing complexity of medical technology and the growing number of treatment alternatives mean that gaining informed consent is a challenge to healthcare professionals and patients alike. Healthcare professionals need to help patients through the decision making process, or make appropriate decisions on their behalf, to ensure that that the patient receives appropriate and optimal care. Patients need to ask questions and think carefully about their options to ensure that where ever possible the goal of treatment is what they value most.

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Tracey Phelan

Sources

Faden, Ruth R. & Tom L. Beauchamp. *A History and Theory of Informed Consent*. New York: Oxford University Press, 1986.

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- euthanasia
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Not-For-CPR: Practice and Problems

It is difficult for our society to accept that medical science cannot cure everything. The institution of not-for-CPR orders for the terminally ill is one step towards this acceptance. This article will look at the concept of not-for-CPR orders examining both the practice and problems.

Introduction

Cardiopulmonary resuscitation (CPR) is a medical intervention for restoring circulation and respiration in an emergency situation following cardiac arrest. A strict definition is difficult because CPR can vary according to the time, place, and the relative health of the person who has arrested: it can mean simple cardiac massage and mouth to mouth resuscitation on someone in the street as well as, in a hospital situation, the administration of drugs and adrenalin, and electric shocks. While CPR can be very effective in some situations, there are doubts as to its efficacy in others. According to some statistics, the chances of surviving to leave hospital following CPR is only 1 in 7: the American Medical Association guidelines say that 85% of patients who receive CPR in hospital do not leave the hospital alive.

“the procedure must be considered futile on medical grounds”

Consequently, more and more hospitals are starting to institute not-for-CPR orders on those patients for whom CPR is considered a futile procedure. Not-for-CPR needs to be distinguished from other acronyms such as DNR (do not resuscitate) and NFR (not for resuscitation) which may apply to other resuscitation situations: DNR and NFR can be open to misinterpretation and should to be avoided. The times when a not-for-CPR order is made will vary from hospital to hospital. Some hospitals have no not-for-CPR policy and will automatically institute CPR procedures on any patient who goes into arrest. Other hospitals have specific guidelines that must be followed: the procedure must either be

considered futile on medical grounds, or it must be considered that the patient would have such a poor prognosis that the distress caused by CPR would be disproportionate to the result. If a not-for-CPR order is considered warranted and is in place for a particular patient, then that patient will not be resuscitated in the case of cardiac arrest.

Some of the doubts about CPR and its efficacy can be illustrated by the case of Mr. X, taken from the *Cambridge Quarterly of Healthcare Ethics*. This case highlights some of the main issues that beset patients, their families, and healthcare professionals, in the crucial decision of whether and when to institute a not-for-CPR order.

The Case of Mr X

Mr. X was a 63 year old man admitted to hospital with fever, respiratory distress and recurrent pneumonia. He had also had emphysema for 10 years and in hospital his status worsened to the point of respiratory failure. He suffered a cardiac arrest while on a ventilator in intensive care, was resuscitated with CPR, but never regained consciousness. A tracheostomy was performed (opening an airway in the throat), a nasogastric tube inserted (feeding tube down the nose and into the stomach) and after 3 months he was diagnosed as permanently unconscious. Over the next year he was treated several times for severe infections and pneumonia. Medical staff believed that a not-for-CPR order was warranted: another resuscitation attempt would be futile and he would be better off in a chronic care facility where he would receive compassionate end-of-stage care. However, Mr X's wife, invoking her Jehovah's Witness faith, refused to “give up” on him,

insisting that any life was better than no life. Because of this situation, medical staff could not agree amongst themselves as to the best option and as they rotated through the hospital he was declared for-CPR and then not-for-CPR several times. Eventually one night he was found to be without vital signs and a CPR team was called in to resuscitate him. The team elected not to attempt CPR as he had probably been without vital signs for more than 30 minutes.

Lack of Consensus

The first issue that this case highlights is the problems that occur when the wishes of a patient or their agent clash with the decisions of the healthcare workers. Often, at the end stages of life a patient, or a patient's representative will *wish* to withdraw from invasive or futile treatment, and under Victoria's *Medical Treatment Act 1988*, they are entitled to do so: if the patient or agent wishes to refuse CPR then a “Refusal of Treatment” certificate can be filled out, and placed in their medical records. (For further discussion of the right to refuse medical treatment, see “Refusal of Medical Treatment” in volume 2, issue 2 of *The Bulletin*). Such a decision makes the situation easier for everyone.

However, what happens when the medical staff believe that CPR would be unwarranted and they believe that on medical grounds a not-for-CPR order should be instituted, but the patient, their agent or their family does not agree with them, as happened in the case of Mr X? Should the medical team discuss the issue with them, and then tell them that regardless of their wishes they will be instituting a not-for-CPR order anyway, or should they not discuss the issue with the patient or family at all

or, finally, should they accede to the wishes of the patient or family against their own medical judgement? The first two options sound paternalistic and, on the surface, look like they clash with the concept of patient autonomy: the right of a person to make his or her own deci-

“demands for futile treatments can be very frustrating for medical staff”

sion about their life is an important one in our society.

Nevertheless, demands for futile treatments from patients or their agents can be very frustrating for medical staff. It must be recognised that autonomy, while right, is not an *overriding* right and that while a patient has a right to know what decisions are being made, they do not have a right to demand a specific treatment that a medical team considers completely medically unwarranted. In the case of a competent patient, the situation should normally be discussed with them and the rationale explained. In the case of an *incompetent* patient, while a discussion with relatives is important, relatives have no legal right to make decisions with respect to treatment unless they have been legally appointed. Even when legally appointed, they do not have a right to demand treatment that goes against the medical opinion of the doctors. The decision remains a medical one to be made by the medical team involved. In the case of Mr X, above, while the medical team were sympathetic to Mrs X's reasoning, they should not have felt bound by it.

Futility

The second issue that the above case highlights is the problem of defining “futility”. There are two kinds of futility: qualitative futility refers to the quality of life that the person receiving CPR is likely to have after the procedure; quantitative futility refers to the probability – or lack of – of the patient surviving a CPR procedure. In the case of Mr X, it could be argued that the first CPR

he received was qualitatively futile, in the sense that it simply resulted in

“while we have a duty to preserve life, there is no duty to go to unreasonable and unnecessary lengths to do so”

him being permanently unconscious, surviving only on artificial feeding. Some argue that any kind of life is sacred and that we have a duty to preserve it for as long as possible: Mrs X as a Jehovah's witnesses believed this, hence her refusal to countenance a not-for-CPR order on her husband even after it was established that he would never regain consciousness. To her, the original CPR was not a futile procedure and another one would not be futile either. Others argue that, while we have a duty to preserve life, there is no duty to go to unreasonable and unnecessary lengths to do so and that consequently Mr X should not have received the first CPR.

The desire to institute a not-for-CPR order following Mr X's diagnosis of being permanently unconscious was based on the fact that it was quantitatively futile: the chances of surviving the procedure were so negligible as to be regarded as pointless. While some, such as Mrs X, would say that even the remotest chance is worthwhile, others suggest that a line needs to be drawn somewhere. It is to end this confusion that a definition of futility needs to be specific and, callous as it sounds, if the medical team agrees that a situation is futile, people must learn to let go.

Communication

The third problem that the case of Mr X highlights is that of communication and documentation. It is clear that, even when there was consensus in the healthcare team that the best option was to institute a not-for-CPR order on Mr X, that this was not communicated to other members of staff. If the initial team who had made the decision had clearly documented this, relayed it to everyone who was involved in

care for Mr X, and had carefully explained the reasoning to Mrs X then the later problems may not have occurred. As it was, it remained unclear right until the end when a CPR team were called, whether or not Mr X was to be revived or not, in the event of a cardiac arrest.

Conclusion

Not-for-CPR is an emotive issue. It is difficult for our society to accept that medical science cannot cure everything and that there are situations when it is time to let go. Victoria's *Medical Treatment Act*, in recognising that patients have a right to refuse medical treatment, took a step towards this recognition. Not-for-CPR orders are the next step. As is discussed by Ann Alpers and Bernard Lo in the *Journal of the American Medical Association*, “In our experience, almost all disagreements are resolved after physicians appreciate the patient's or family's goals for care, respond to their concerns, correct their misunderstandings, reassure them that appropriate care will be provided, and allow them time to accept bad news. In intractable disputes, physicians should not have to provide interventions that are futile.” †

Anna Stokes

Sources

Alpers, Ann et al. “When is CPR Futile?” *JAMA* 2/273 (1995), 156.

Caplan, Arthur L. “Odds and Ends: Trust and the Debate Over Medical Futility.” *Annals of Internal Medicine* 125 (1996), 688.

Coogan, Michael. “Medical Futility in Resuscitation: Value Judgement and Clinical Judgement.” *CQ: Cambridge Quarterly of Healthcare Ethics* 2 (1993), 197.

Curtis, J. Randall et al. “Use of the Medical Futility Rationale in Do-Not-Attempt-Resuscitation Orders.” *JAMA* 2/273 (1995), 124.

Grant, Edward R. "Medical Futility: Legal and Ethical Aspects." *Law, Medicine & Healthcare* 4/20 (1992), 330.

Hardwig, John. "Is There a Duty to Die?" *The Hastings Centre Report*

2/27 (1997), 34.

Medical Treatment Act 1988 (Vic). Not for CPR Guidelines. Cabrini Hospital. Malvern, Victoria.

Plueckhahn, Vernon D. et al. (eds). *Law and Ethics in Medicine for Doctors in Victoria.* Melbourne: V.D.

Plueckhahn, 1994.

Schneiderman, Lawrence J. et al. "Medical Futility: Response to Critiques." *Annals of Internal Medicine* 125 (1996), 669.

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