

FACTORS IN DECISION-MAKING CONCERNING LIFE SUPPORT THERAPY

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ABSTRACT

The ability of modern technology to sustain life for an indefinite period creates several questions in this regard. In the same way that values and norms in the broader community have changed, the nurse's role has also changed to becoming an active participant in decision-making and an advocate for the patient. Withdrawal of life support therapy is a sensitive issue and becomes more complicated as more people become involved.

The aim of this study is to explore and describe, from a holistic interactive approach, the factors influencing the decision to withdraw life support therapy. A qualitative, exploratory, contextual, phenomenological case study design was chosen. Factors on the micro level were identified from the case study and factors on the meso- and macro- levels were identified from exploration of literature. The findings of both the case study and literature exploration are presented as a list of factors influencing the decision concerning the withdrawal of life support therapy.

OPSOMMING

Moderne tegnologie het dit moontlik gemaak om lewe vir 'n onbepaalde tydperk te verleng, maar ongelukkig bied dit nie antwoorde op vrae wat in sulke situasies ontstaan nie. Op dieselfde wyses waarop waardes en normes in die breë gemeenskap verander het, het die verpleegkundige se funksie ten opsigte van die aktiewe deelname in die besluitneming van die pasiënte verander. Die staking van lewensondersteunende terapie is 'n sensitiewe saak en word meer gekompliseerd namate meer persone aan die besluitnemingsproses deelneem.

Die doel van hierdie studie is om die faktore wat besluitneming oor lewensondersteunende behandeling beïnvloed, te identifiseer. 'n Kwalitatiewe, kontekstuele, fenomenologiese gevallestudie ontwerp is as ontwerp gekies. Faktore op mikrovlakke is van die gevallestudie en faktore op die meso en makrovlakke deur 'n uitgebreide literatuurverkenning geïdentifiseer.

Die bevindinge van beide die gevallestudie en literatuurverkenning is as 'n lys van faktore wat besluitneming ten opsigte van staking van lewensondersteunende terapie

beïnvloed aangebied.

BACKGROUND, RATIONALE AND PROBLEM STATEMENT

The withdrawal of life support therapy is a reality in intensive care units. Modern technology makes it possible to sustain life for an indefinite period, but provides no answers to questions about quality of life, suffering or the allocation of scarce resources. These difficult decisions still need to be made by human beings. It is a reality that cannot be avoided by nurses.

According to the SA Nursing Act (1987) the nurse is an independent practitioner and is responsible and accountable for her acts and decisions. To act responsibly the nurse actively participates in decision-making concerning the patient in her care. Nurses in intensive care units are not orientated towards ethical aspects and find it particularly difficult to participate in decision-making of an ethical nature (Catalano, 1991:20).

Traditionally the medical practitioner made all decisions concerning a patient's treatment. In modern times the patient has the right to self-determination and autonomy (Strauss, 1993:198) and is therefore included in decision-making concerning his/her treatment, even life support therapy. In this study the involvement of the medical practitioner, nurse and patient in the decision-making process reflects the interactive approach.

Several studies addressed the issue of life support therapy, but they did not include all the role players in this delicate situation. Most of the studies were one-sided, focusing on either the nurses or the medical practitioners, excluding the patient and his/her family. In view of the increasing autonomy of the patient, the patient and his/her family cannot be excluded in studies of decision-making concerning life support therapy.

The patient and his/her family involved in decision-making concerning life support therapy is sometimes subjected to ultimate moral conflict (Morris, 1992:223). The nurse is more familiar with the needs and wishes of the patient and his/her family, because of the nurse's sustained involvement with them. The nurse's role as patient advocate becomes prominent here.

This situation complicates the role of the nurse. Not only is she involved in decision-making concerning life support therapy but as patient advocate she also assists and supports the patient and his/her family in their decision-making.

The more people are involved in decision-making the more complicated the situation becomes. Interaction between role players also has an influence on the decision-making process. A holistic approach is needed to include all these factors in decision-making. The main approach of previous

studies was to find indicators for withdrawal of life support therapy. If the patient is regarded as a bio-psychosocial being, the physiological, psychological and social aspects should be included in a holistic approach.

Previous models of decision-making consisted mainly of steps in decision-making (Greipp, 1992:734). A decision is an act preceded by a network of factors. Knowledge of these factors can assist the nurse in clarification, accompaniment and support of the patient and his/her family, and in a better understanding of the nursing practice.

From a holistic, interactive approach the question arises: What are the factors influencing decision-making concerning life support therapy?

AIM OF THE STUDY

The aim of this study is to explore and identify the factors influencing decision-making concerning life support therapy in an interactive, holistic approach.

DEFINITION OF CONCEPTS

Factors: Factors are the circumstances, facts or causes that influences decision-making concerning life support therapy from a holistic and interactive approach. It is an indication of direction in the decision-making process.

Life support therapy: It is the treatment that maintain the vital functions of a patient that is critically ill. It involves all the measures without which the patient would probably die. In this study it includes the use of positive inotropes, mechanical ventilation, dialysis, antibiotics and/or vasodilators. It excludes the patient who is brain-dead.

Decision-making: The cognitive process utilised to come to a conclusion when a person is confronted with an ethical dilemma.

DESIGN AND METHOD OF THE STUDY

A qualitative, contextual, retrospective, exploratory case study design was used. To identify the factors from a holistic interactive approach, the research design is divided into the macro-, meso- and micro levels (Jones as adapted by Botes, 1995). The government of South Africa and the broader society constitute the macro level, the professional level constitutes the meso level, and on the micro level are the individuals involved in decision-making, that being the patient, his/her family and the members of the health team.

Factors in the meso and macro levels were identified by means of a literature review. A case study was done to explore and identify the factors influencing decision-making concerning life support therapy on the micro level. The methods of sampling, data collection and data analysis for the micro level are discussed below.

Population and sampling

The sampling in this study was purposive (Uys & Basson, 1983:65-72), and the boundaries of the case is determined by the nature of the problem investigated (Merriam, 1992:9). One case was selected (n=1) on the following criteria:

- The patient is critically ill and needs extensive, intensive therapy, i.e. inotropic support, mechanical ventilation and/or dialysis.
- The medical practitioners involved with the patient verbalise their uncertainty regarding his/her prognosis.
- The patient and his/her family are English or Afrikaans speaking for interviewing and observation purposes.
- In order for the researcher to understand the person's cultural values and interpret it in the context, the patient and his/her family is of Western culture.
- Level of consciousness is not considered since most critically ill patients in intensive care units have an altered state of consciousness.
- The patient gives written consent (if possible), as well as all people involved with the patient.

Methods of data collection

Various methods of data collection were used in the case study, namely interviewing (Polit & Hungler, 1991:277-297), observation (Uys & Basson, 1983:65-72) and document analysis.

The case study framework (refer to table 1) constitutes the content of the case study. It is based on the Nursing Theory for the Whole Person (Rand Afrikaans University, 1992) and adapted for relevancy in this study.

Data analysis

Data was collected during interviews, observations and document analysis. During the process of data analysis, this data was reduced to themes (factors in this study) and placed into categories according to the principles of Tesch (Creswell, 1994:153-161). The data collected is presented as a narrative, as it would be too long, comprehensive and complex in any other way. The narrative is checked to ensure that all factors identified from the raw data is present in the narrative and that it is accurate. Data analysis is done by the researcher and an independent experienced external coder.

Validity and reliability

Following the method of Lincoln and Guba (1985:289-331) for qualitative studies ensures validity and reliability.

Ethical aspects

Due to the sensitive nature of this study, the ethical aspects need special consideration. The guidelines of the professional nurses' organisation in South Africa were followed (South African Nurses Association, 1991).

Table 1. Summary of case study framework, sources of data and method of data collection.

CONTENT	SOURCES	METHOD
MICRO LEVEL		
1. Identifying data	Documentation	Document
- Name	Patient	Structured interview
- Patient number	Family	
- Date of birth		
- Age		
- Sex		
- Religion		
- Medical aid		
- Residence		
- Medical aid details		
- Occupation		
- Composition of family		
- Doctors involved		
- Date of admission		
- Period of hospitalisation		
2. Internal environment		
2.1 Physical	Documentation	Document exploration
- Disease	Members of Health team	Semi-structured interview
- Support measures		

<p>2.2 Psyche</p> <p>(of all role players)</p> <p>Cognitive</p> <ul style="list-style-type: none"> - Level of consciousness - knowledge and understanding of disease - knowledge and understanding of prognosis - decision-making ability <p>Emotional experience</p> <p>Motivational aspects</p> <ul style="list-style-type: none"> - motivation - priorities <p>Spiritual (all role players)</p> <ul style="list-style-type: none"> - role of religion - view of life/dying/death - man-world view 	<p>Patient</p> <p>Family</p> <p>Members of Health team</p> <p>Patient</p> <p>Family</p> <p>Members of Health Team</p> <p>Patient</p> <p>Family</p> <p>Members of health team</p> <p>Patient</p> <p>Family</p> <p>Members of Health team</p>	<p>Semi-structured interview</p> <p>Observation</p> <p>Semi-structured interview</p> <p>Observation</p> <p>Semi-structured interview</p> <p>Observation</p> <p>Semi-structured interview</p> <p>Observation</p>
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3. External environment		
3.1 Physical environment	Intensive care unit	Observation
- sources available	Unit philosophy	Document
- privacy	Unit Policy	Expolration
- isolation	Unit manager	Semi-structured intetview
3.2 Social		
- financial aspects	Patient	Semi-structured interview
- influence of disease on work and lifestyle	Family	Observation
	Members of health team	
3.3 Spiritual		
- influence of church	Patient	Semi-structured interview
- family relations	Family	Observation
- roles in the family	Members of health team	
- relationship with carers		
- relationship of members of the health team with the patient and family	Patient	
	Family	Semi-structured interview
	Members of health team	Observation

FINDINGS OF THE STUDY

The findings of the macro-and meso levels are presented as a literature review and the findings of the micro level are presented as a narrative.

Macro and meso levels: literature review

A literature review was done to explore and identify the factors influencing decision-making concerning life support therapy on the meso and macro levels.

Macro level

The health care system

Nursing is a part of the health care system and is influenced by the policies and laws thereof. The current government has a National Health Plan (African National Congress, 1994) directing policies regarding health care. It is based on various principles of which a few that bear relevance for this study will be discussed. *The right to health* is seen as a basic human right and it is the duty of the government to provide it. The right to health became an issue because of the inaccessibility of health care due to social, economic and geographic factors in South Africa.

Primary health care is the underlying philosophy for the restructuring of the health care system (African National Congress, 1994). The exact balance between primary, secondary and tertiary care is currently under debate. The more expensive curative services must be rationalised rather than decreased which requires some discernment in decision-making (Basson, 1994:20).

The appropriate use of technology has been identified as an important factor in the success of the health care system (African National Congress, 1994). There is currently an overuse of expensive technology (Deeb, 1993:54) and a balance is required between the technology of the First World and the needs of the Third World component in the community.

Priorities, which mostly include primary health care and promotion of health, have been set. Priorities play a major role in the financing of the health system. As a result of the need for welfare services and limited funds (Basson, 1994:20), little financing is available for secondary and tertiary health services.

Human rights

The basic rights of individuals are guaranteed in a Bill of Rights, included in the Constitution (Nel, 1993:179). These rights include equality, life, human dignity, freedom and security, privacy, religion, freedom of belief and opinion, freedom of expression, freedom to assemble, freedom of movement, freedom of residences, administrative justice, economic activity, fair labour practice, property, a healthy environment, right to own language and culture, education as well as children's rights (Poggenpoel & Muller, 1996:9).

Culture

South Africa has a divided and pluralistic environment due

to a long period of limited social contact between groups, no exchange of intellectual thoughts and no shared education (Taitz, 1993:443). This leads to a situation of cultural differences between nurse and patient. Culture gives direction to thoughts, acts and decisions in a specific way. Individual values are influenced by family habits, religion, cultural and educational background and peer group influences (Pera & Van Tonder, 1996:177,189).

Religion as a part of culture plays an important role in health. It influences the thoughts and behaviour of the ill, the dying and the relatives (Pera & Van Tonder, 1996:177,189). It is not appropriate to describe all the different cultural and ethnic groups in South Africa in this document. Sensitivity and flexibility is needed in every situation.

Legislation

Legislation can be divided into the common law, statutory law and court rulings. Only the statutory law will be described.

Technically the withdrawal of life support therapy is seen as murder (South African Law Commission, 1994:11; Strauss, 1991:338; Skegg, 1988:139), although no clear laws exist in this regard. The courts are guided by the "boni mores", the convictions of a community. This is questionable in a divided and pluralistic community such as South Africa. In most sources though it seems that the termination of fruitless efforts to save a life is not regarded as unlawful (Strauss, 1988:11; Strauss, 1991:323; Taitz, 1993:443).

In 1994 a commission of law was appointed to investigate euthanasia and the artificial preservation of life (South African Law Commission, 1994:59). Their recommendations form the basis of the following discussion of statutory requirements for the withdrawal of life support therapy.

The commission's point of departure can be summarised as follows: In the case where a person's condition reached the point where purposeful life is not possible any more and there is no prospect of recovery, it is not unlawful to terminate a person's life, even through a positive action and in the absence of that person's consent (South African Law Commission, 1994:33).

They posed the following guidelines:

- the doctor is convinced that the patient's disease causes severe suffering, and there is no reasonable prospect of recovery, or
- the patient is in a constant state of unconsciousness, and the doctor does not foresee the possibility that the patient will ever lead a reasonable life, and
- this state of affairs is confirmed by at least one other doctor not involved in the treatment of the patient.
- The doctor keeps written record of his/her findings and conduct.
- The medical superintendent of a hospital can also give his/her consent to withdraw medical treatment from a patient in the above mentioned conditions. Confirmation by a second doctor is also required.

- The doctor can not act against the wishes of the patient's family.

The Medical Association of South Africa disagrees with the fact that the consent of the family is necessary because of the influence thereof on scarce resources (Anonymous, 1994a: 26). This is confirmation of the belief that this is an economical and clinical decision.

The unnatural termination of life is still regarded as illegal by the South African Council of Nursing which states that neither a living will nor a request by another registered person can force a nurse to stop life support therapy (South African Nurses Council, 1992).

Since nurses are independent practitioners and as part of the health team included in decision-making, it is vital that the nurses are aware of the legal requirements and act accordingly.

The activities, policies and laws on the macro level influence the meso and micro levels, but because of the dynamically and rapidly changing situation in South Africa, the precise influence of this is still uncertain.

Meso level

The nurse makes decisions in the nursing context. The practice guidelines and values influence these decisions.

Laws with relation to the nursing practice.

Although these laws are also statutory laws they are discussed on the meso level due to their direct relevance to nursing.

The legal framework encompasses all other frameworks; therefore no decision can be made outside the legal framework (Botes, 1994:66). Laws stand in a special relationship to ethics: Laws are binding and prescribes punishment. Breaking of ethical codes is not punishable, but laws cannot enforce moral behaviour (Botes, 1995:7). The law of primary interest for the nurse is the Nursing Act.

• The Nursing Act (Act 50 of 1987, as amended).

This act regulates the nursing practice and places regulation of the profession in the hands of a statutory body. The Nursing Act empowers the Professional Council to regulate nursing practice professionally and ethically, leading to the enactment of Regulation 2598, as amended: regulations relating to the scope of practice of persons who are registered or enrolled under the Nursing Act, 1987 (Pera & Van Tonder, 1996:6). The Nursing Act also empowers the South African Nursing Council to stipulate the Rules setting the acts or omissions in respect of which the Council may take disciplinary steps (Regulation 387). A short description of the influences of these two regulations in decision-making concerning life support therapy follows from the above.

The nurse is an independent practitioner, implying that she prescribes nursing care, decides on the acceptance of prescriptions from other registered practitioners and is responsible for scientific-methodical nursing. She is responsible

and accountable for all her nursing actions.

In scientific-methodical nursing she is responsible and accountable for the prescription, supply and administration of a nursing regimen, using the following steps: assessment, diagnosis, planning, implementing and evaluating of nursing care.

The nurse also makes a decision concerning the prescriptions of another registered practitioner. Her knowledge and skills regarding the implementing of the prescription and the correctness of the prescription in a legal, ethical and philosophical framework, are the criteria for carrying out the prescription. If she decides to accept a prescription, she is responsible and accountable for this decision and for carrying it out. She can refuse any prescription not regarded as in the best interests of the patient (South African Interim Nurses Council, 1992). If she refuses to follow a prescription, she must inform the prescribing practitioner as soon as possible. There are certain basic needs each patient has, which the nurse always provides for, namely hygiene, physical comfort, re-assurance, exercise, rest, sleep, facilitating of bodily mechanics, prevention of bodily deformities, facilitating of healing of wounds and fractures, protection of the skin, maintenance of sensory functions, feeding and supervision over and maintenance of elimination. In the context of the intensive care unit certain of these functions is of special importance and will be discussed briefly.

Monitoring is part of both assessment and evaluation of the patient and is a continuous process in the intensive care unit. The nurse is responsible for the monitoring of the general health status of the patient and specifically of the vital signs, reaction to disease conditions, trauma, anxiety, medication and treatment.

The nurse assesses the patient and makes a nursing diagnosis. According to her knowledge and skills she decides whether she will act herself or *refer the patient to another registered practitioner*. It is stated emphatically in R387 that she may not delay in referring the patient should his/her condition require it.

The doctor prescribes medication according to the Medical, Dental and Supplementary Health Service Professions Act, 1974. In the execution of a program of treatment and medication, the nurse is responsible for *the correct administration of medication* and the monitoring of the patient's reaction. In an emergency the nurse may have to administer medication in an effort to save a life, prevent deterioration of the patient's health status, to prevent deformities and to minimise pain and suffering.

Oxygen is a basic condition for life. Various methods of *administering oxygen*, varying from simple positioning to mechanical ventilation, are available in the intensive care unit. Not only must the patient be able to inhale enough oxygen, but that oxygen must also be able to reach the tissues, implying measures to ensure cardiac output and adequate hemoglobin. The administration of oxygen is an emergency

procedure and the nurse must do everything in her ability to prevent cessation thereof (Searle, 1987:190).

In the intensive care unit advanced measures are available to *supervise over and maintain the fluid, electrolyte and acid base balance of the patient*. Hydration of a critically ill patient is of cardinal importance requiring the administration of the correct fluid (via any route), bloodgas analysis, administering of prescribed medication and diet. Feeding is a basic need including enteral and parenteral feeding. Actions such as catheterisation and dialysis are also involved in the monitoring and maintenance of fluid status.

Communication is important. The patient in the intensive care unit requires special reassurance and support in the process of seeking bodily, psychological and spiritual wholeness. Communication between the members of the health team is vital as part of the nurse's role of co-ordination, referral and co-operation.

As patient advocate, the nurse is the voice of the patient to ensure he gets the care he needs (Searle, 1987:201). This means communicating the patients needs to others when he is not able to, including his/her wishes as stipulated in a living will.

In the *care of the dying and the recently deceased*, the nurse accompanies the patient and supports the family with sensitivity to cultural differences.

All the aspects of nursing care in the intensive care unit is included in the *facilitation and maintenance of the bodily regulatory functions of a patient*. The nurse maintains a holistic perspective, uses the full spectrum of her knowledge and skills and does not perform any actions for which she does not have adequate training.

• Other acts influencing nursing practice

Not only is the nurse an independent practitioner as described in the previous section, she is also part of the health team and in order to facilitate co-operation, referral, co-ordination and consultation, she also knows the scope of practice of the other practitioners (Botes, 1994:69).

The Medical, Dental and Supplementary Health Service Professions Act, 1974 stipulates that nobody may practice as doctor unless he is registered according to this act. The nurse is responsible for making a nursing assessment and diagnosis of the patient in order to nurse scientific-methodical. The doctor makes a medical diagnosis and prescribes medical treatment and medication.

The practice of the nurse is comprehensive and many other laws, such as the Act on Human Tissue and the Medicines Act bear relevance to the nurse.

Nursing ethics and codes

Acts and legislation regulates the nurse's acts and omissions but not her attitude (Nel, 1993:168). Nursing ethics shares similarities with medical ethics but is a study in its

own right. Nursing ethics is stimulated by the changes in the social and professional hierarchy, by questions generated by the study of ethics and by medical and technological development. Ethics in this study is the branch of philosophy concerned with morality, integrity and that which we should do (Botes, 1989:56).

Ethical codes include the general guidelines accepted by the nursing profession as suitable in the making of ethical decisions. It sets the rules and moral standards applicable to nursing behaviour and is a proclamation to the public (Pera & Van Tonder, 1996:4-5). It states the general rights, duties, values, policy directions and standards for behaviour expected of members of the profession (Thompson, Melia & Boyd, 1988:57-58). The breaking of an ethical code is not a criminal offence but corrodes the trust between the nurse and the public (Botes, 1989:56). Ethical codes are taken into consideration in the interpretation of laws (Edgar, 1994:160). The Pledge of the nurse/midwife (South African Nurses Association) is an example of such an ethical code.

Ethical theories

Every ethical theory has its own ethical viewpoint and provides guidelines in the analysis, discussion and conceptualisation of each ethical dilemma in the nursing practice (Pera & Van Tonder, 1996:18-21). The two most important ethical theories are consequentialism and non-consequentialism.

• Consequentialism

Consequentialism implies that the right or wrong of an action depends on the value or consequences it holds for the self, everyone and for some (Pera & Van Tonder, 1996:22).

Utilitism evaluates an ethical action as the one that brings the best long-term consequences for everyone or the most people involved, looking for a balance between good and bad, benefit and damage. The nurse's main responsibility is her patient and this approach may be regarded as problematic (Husted & Husted, 1995:13).

Limited consequentialism evaluates the value of an action by the consequences it brings to the individual person or number of individuals, for example the best balance between good and bad for the patient (Pera & Van Tonder, 1996:22). The problem is when the situation occurs where the interests of individuals are set above those of the community. It may also be in conflict with the patient's right of autonomy.

• Non-consequentialism (deontology)

According to this theory a person is behaving ethically when he is doing his/her duty. The nature or form of the actions determines the right or wrong of the action. The "goodness" of an act is not taken into consideration (Pera & Van Tonder, 1996:22). However, dispute exists about what duty is (Singleton & McLaren, 1995:17-18) and which duties have precedence in conflicting situations. Many of the ground rules of nursing are deontologically orientated. According to this approach a nurse is behaving ethically if

she follows the regulations as described in her scope of practice.

Ethical principles

The complexity of situations requires a non-pragmatic approach and a study of ethical principles (Pera & Van Tonder, 1996:22). People of different ethical approaches are sometimes required to make a joint decision.

Autonomy is the respect for the unconditional value of a person and respect for individual thoughts and actions, the rational abilities of an individual and his/her right to self-determination (Husted & Husted, 1995:38-40). Both of the above mentioned ethical theories respect the individual's right of autonomy (Gillon, 1986:64). It is regarded as the highest of all ethical principles (Thompson, Melia & Boyd, 1988:88). It includes telling the truth, privacy, confidentiality, informed consent, refusal of treatment and suicide. There is, however, a problem in a situation where the patient is not able to make his/her own decisions. The principle of autonomy stands directly opposite to the traditional paternalism in the medical culture.

In practice it is difficult to distinguish between benevolence and non-malevolence as ethical principles. Both stem from the earliest traditions in nursing. Benevolence is the duty not to harm and non-malevolence is the duty to promote good. This includes bodily, emotional, spiritual, moral or any other harm. It protects the individual's reasonable expectation that the health system would be of benefit for him (Pera & Van Tonder, 1996:22).

Justice can be seen as just, proportional treatment rather than equality (Gillon, 1986:87). It includes the principles of allocation of resources and fairness. Sometimes justice opposes the autonomy of a person: limiting the rights of an individual for the sake of the community.

The ethical principles do not provide definite answers, since they oppose each other at times. It is the individual that decides on the importance of a specific principle (Rumbold, 1993:202).

Existing standards in practice

The need for intensive care treatment is increasing but expensive and scarce resources are shrinking. This creates pressure on the medical fraternity to reduce the cost of medical care and apply justice in allocation of these resources (Knauss, Wagner & Lynn, 1991:389). In view of this pressure research efforts are concentrating on seeking guidelines to predict functional outcome.

APACHE is an acronym for "Acute physiology and chronic health evaluation". It is used widely in the prognostic stratification of patients. Physiological variables are put on a scale together with age, gender, operative status and primary organ dysfunction (Marks, Simmons, Blizzard & Brown, 1991:159). In spite of its widespread use it is yet not 100% accurate and observer mistakes still occur (Knauss, Wagner & Lynn, 1991:390), and it is of limited value in

50/50 cases where decision-making is crucial (Luce & Wachter, 1994:229).

Qaly's is the acronym used for "Quality adjusted life years". It is developed to fulfil the needs for distributive justice in health care (Rumbold, 1993:182) and is calculated as follows: the Qaly-value is the number of Qaly's with treatment minus the number if not treated. The best outcome has the most Qaly's. Qaly's put the focus on the cost of health care; it accentuates the need for the measurement of outcome of medical care and the principle of justice. The problem however, is that the sicker a patient is, the less he is entitled to health care. The other problem is that limited criteria are used to measure quality of life and is of limited value in the issue of quality of life.

It is therefore clear that, although these standards have been developed to provide answers in decision-making concerning intensive care and also life support therapy, it is of limited use in practice. It reduces the human being to a body alone and does not take psychological, spiritual and social factors into consideration. However, it is valuable in reducing practitioner's bias (Knauss, Wagner & Lynn, 1991:390).

Decision-making

The nurse, the patient and his/her family are involved in the process of decision-making. Decision-making for the nurse has always been approached in the context of a process with different steps (Greipp, 1992:734-738). The majorities of these are related to the nursing process and encompass several steps: assessment, problem identification, and consideration of different actions, implementing and evaluating. The application of a model of decision-making does not guarantee a morally justifiable decision. It provides a systematic way of rational decision-making with clear reasons and justifications.

The patient and his/her family are also in a process of decision-making. In all probability they did not have training in ethical decision-making and have a different approach to the situation as opposed to the nurse's more systematic approach. Decisions are motivated and are directed by knowledge, attitudes, value and opinions, and are also directed at fulfilment of various needs (Kreigh & Perko, 1988:82). Other factors that may influence the person's ability to make a decision are anxiety, medication, metabolic disturbances and sensory overload (Rushton, 1994:103). The decisions the patient and family make may not always be morally justifiable, but are personally and emotionally meaningful.

The above is a short summary of a literature review of the factors in decision-making concerning life support therapy. It explores the factors on the macro and meso levels.

Micro level: narrative

The data of the case study (micro-level) is presented as a brief narrative. People used in this narrative are fictitious to protect all role player's rights.

Mrs C Du Toit is a 55 year-old married woman who resides in the country. Her husband is also 55 years old and a pensioner. They have four married independent children. Beth stays in the city while Ronel, Peter and Carin live in the same town as their parents.

In January, Mrs Du Toit was admitted to the local hospital with respiratory distress. She was eventually transferred to the intensive care unit of a hospital in the city. She was dismissed with oral steroids after 18 days in the intensive care unit. She also suffered from chronic ulcerative colitis and received a new medication for the condition. This new medication aggravated the symptoms of diarrhoea. She developed symptoms of an acute abdomen and was admitted to the local hospital once again, where a laparotomy for obstruction was performed. As a result of infection and poor wound healing she was transferred once again to the intensive care unit of the city hospital on 12 September.

On 15 September, the radiological tests indicated perforation of the small intestine. An intestinal resection was performed the same day. It was found that the small intestine did not heal and that the abdomen was filled with faecal matter. On 22 September she was taken to the theatre for abdominal irrigation. At the same time a tracheostomy was performed.

She progressed well initially and the mechanical ventilation rate was reduced to 2 per minute. She received maintenance infusions, antibiotics and renal dosage dopamine. Midazolam infusion was continued until 24 September and the morphine infusion until 26 September. She was fully conscious and orientated in respect of time, place and person. By 4 October she gradually became confused and lost consciousness. Communication with her has been impossible since that day.

Her physical health deteriorated. Dobutamine was resumed for a couple of hours on 8 and 9 October. Since 10 October it was administered uninterruptedly. Adrenaline infusions were administered since 4 October. Since 4 October she did not pass urine. The diagnosis was renal failure, hepatic failure and respiratory failure as a result of sepsis.

Mr Du Toit was at his wife's bedside throughout the day. He spent the nights with his daughter, Beth, who lives in the city. Beth takes him to the hospital every day.

On 5 October, the possibility of withdrawing the treatment was discussed with Mr Du Toit and Beth. Dr Meyer explained that he was of the opinion that further treatment such as dialysis would be of no use since she did not react to the present treatment. Mr Du Toit and Beth would give their decision to Dr Meyer after lunch.

After consulting with the other children, the family decided unanimously not to withdraw treatment. The family advanced various reasons for this decision. Among others, they felt that she was very ill the last time and that she had recovered. Ronel believed that it would boil down to murder

and this was unacceptable to her. The family felt that they did not possess the necessary knowledge for such a decision and to them it was unthinkable to expect it of them. They believed that God alone could decide about life and death. The family also considered the possible wishes of Mrs Du Toit in their decision.

Mrs Du Toit's blood pressure improved to such an extent that afternoon that Dr Meyer decided to continue the full treatment. Since 6 October she received haemodialysis. Dr Meyer was of the opinion that a lot of uncertainty existed about sepsis and that one therefore had to be careful. There was no guarantee that a decision was the right one.

The unit manager, Mary, disagreed with the decision. She was of the opinion that it was not fair to the family since they were being given false hope. She believed that it was wrong to mislead the family. The fact that positive inotrope therapy was already ceased also strengthened her belief. Mary also believed that the situation was not fair to the nursing staff who felt uncomfortable about the fact that doctors did not always agree. The involvement of the nursing staff with the patient and family made it difficult for them not to be emotional in their decision-making.

Elsa, a nurse who was involved with Mrs Du Toit for a considerable time, decided to talk to the family about the possibility of withdrawal. Elsa was of the opinion that Mrs Du Toit only had a 5% chance of recovery since she suffered from multi-organ failure and did not react to treatment. Mrs Du Toit was getting thinner by the day. Elsa expressed the fact that she could not stand seeing the family suffer like that any longer. Elsa was also concerned about the enormous medical costs for which the family was responsible. Elsa thought it was absurd to pay for treatment to which Mrs Du Toit did not respond. Elsa also believed that it was wrong to give the family false hope as Dr Meyer did.

However, the family was very upset after their conversation with Elsa. They believed that the nurses were too used to death and that they did not care. They attached a lot of value to the verdicts of Dr Meyer who was very hopeful. It was only later that the family realised that Dr Meyer had given them false hope.

On 16 October, the possibility of withdrawal was discussed once again by the medical team. Dr Meyer was of opinion that she had no prognosis as a result of the multi-organ failure and the sepsis. His view was that further treatment was senseless at that stage. Dr Meyer decided not to talk to the family about the decision. He did not want to make them feel guilty.

Treatment was gradually withdrawn and Mrs Du Toit died the next evening.

FACTORS INFLUENCING DECISION-MAKING CONCERNING LIFE SUPPORT THERAPY

From the data of the macro-, meso- and micro- levels, the following factors influencing decision-making concerning life support were identified.

Availability of sources

Technological appliances are expensive and not freely available. A patient cannot receive life support if it isn't available. Knowledgeable people must use the technology appropriately.

The main emphasis of human resources is on nurses. There must be enough nurses to care for the patient and they must have the knowledge and skills to care for a patient on life support.

Finances can be seen as a limiting factor. The ability of the person to pay for medical services and the availability of funds for the required technology is taken into consideration. All the other factors are limited by the availability of funds.

The health needs of the patient

The patient's need for life support is an important factor. The nurse must assess the patient's health needs and act accordingly. The patient and his/her needs direct decision-making.

The patient's health status

The patient's physical health determines the level of nursing intervention he requires. In this regard the prognostic scales of APACHE and Galy are of value and the physical variables associated.

Knowledge

The knowledge of the health team influences decision-making. Knowledge is needed for rational decisions and is modified by training. The health team must also have the knowledge to use technology in the appropriate way.

Policy, human rights and legislation

The macro level of health policy influences policies on all other levels as it determines the allocation of manpower, resources and finances. The health policies on the meso- and micro-level must be congruent with the policy on macro-level.

Human rights are included in the Constitution of South Africa. There are the rights of the patient and the rights of the patient with special needs that must be taken into consideration. Finances limit the exercising of rights.

Legislation follows policy. The laws to take into consideration are the Nursing Act, the Human Tissue Act, the Medicines Act and The Medical, Dental and Supplementary Health Service Professions Act. These acts clarify roles, duties, responsibilities and accountabilities. Decisions

taken outside this framework has legal repercussions.

Values

Values is a comprehensive term. It includes attitudes, perceptions, practices, religion, and educational background and peer group influences. The values of the individual person influence his/her decision-making, but the values of the community are expressed in the "boni mores", influencing the ways in which laws are interpreted.

Ethical aspects

- The outcome of an act/interaction. This factor includes the principles of benevolence, non-malevolence, and distributive justice. The intention is to act to the good of the self/patient/everyone. It includes the intention to reduce suffering in the dying process. Related to this factor is the ability to predict the outcome, influenced by the prognostic scales and the knowledge of the person making the decision.
- The nature/form of the interaction. The right or wrong of an act is evaluated and decided by the individual. This factor may modify other factors; for example the reason for withdrawal of life support may be valid, but the act required doing this is unacceptable.
- Life beliefs. From the definition it is clear that a patient will probably die without life support therapy, and therefore beliefs regarding life or death are involved in decision-making, for example the value of life in itself versus the quality of life.
- Autonomy. This factor has some prominence as both an ethical principle and a basic human right. It means that the person has the autonomy to make his/her own decisions.
- Justice. The principal factor here is distributive justice and is underlying to most other factors such as allocation of resources, individual rights and policy making.
- The ability to make a decision. There are the legal requirements of being older than 18 years and in his/her right mind. Other factors such as knowledge, skills, sensitivity, intelligence and emotional factors are also involved here.
- The interaction between factors. Not one single factor stands in isolation, each one influences the other. The specific factors in each individual case will influence the other in a dynamic and unique way. Not only do the characteristics of each situation differ, but also the people involved also differ. The continuous changes in the macro - and meso-levels in a dynamic period in South Africa must also be taken into consideration.

The uniqueness of the situation

Ethical situations are complex situations without clear-cut answers as verbalised by the patient's family and the health team members. The lack of previous related experiences influenced the family's decisions since they could not comprehend what was asked of them. The nurse's response was that she had seen similar situations to this and did not want it repeated. The role-players are in constant interaction

with each other and influence each other and the situation. The individual has an influence on the whole.

DISCUSSION

The subject explored in this study is sensitive and complex. A new field of study was opened and the previously neglected areas of psychological and spiritual aspects were included. Involving the patient and his/her family is a new approach. It is shown that a single factor does not give the answers in decisionmaking, but rather the interaction between factors.

This study does not give all the answers regarding decision-making concerning life support therapy as it is a complex subject that is continuously subject to change. Only exploration was done and not an in-depth study of the subject of life support therapy. The factors influencing decision-making concerning life support therapy was identified but not fully analysed or described. As only one case study had been done, there can still be other factors that were not identified in this study. The study is limited to the context and culture in which it was done and transferability is limited. It is recommended that this study be repeated in a different context, for example in a public hospital and with a different cultural group. Studies can also be repeated in the same context to verify the factors identified in this study. Further studies are recommended where the cultural and emotional factors are explored further.

The factors influencing decision-making concerning life support therapy can be used to define the parameters in decision-making concerning life support therapy, in order to describe a model in decision-making concerning life support therapy.

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