



## Review

## End of one's life—Decision making between autonomy and uncertainty

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## ABSTRACT

At the end of life in western medicine often a decision has to be made about treatment options and the therapeutic strategy. The concept of autonomy which forms one of the four ethical principles plays a significant role in the decision-making process. Competing issues can be involved in end-of-life decisions and the patient and his/her relatives are often overwhelmed by the situation. Therefore, a “jointly supported” or “borne autonomy” requires knowledge and open discussion with the physician who is able to provide a clear and concise treatment suggestion which the patient and his/her relatives (“unit of care”) are truly able to follow. Decision making is a step-wise process which ends in a concerted action focusing further procedures based on the “jointly supported” or “borne autonomy”. This kind of autonomy stands against uncertainty and provides end-of-life decisions which enable autonomy and quality of life for the patient and his/her relatives.

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## 1. Introduction

Decisions regarding end-of-life care have become an ever more important and complex part of a clinician's every day work. Amid this complexity and uncertainty, healthcare professionals must strive to make decisions that mediate competing interests with the objective to provide treatment that reduces suffering and improves quality of life. End-of life decision making often involves incomplete clinical information, strong and often conflicting attitudes and judgments of patients, family, and healthcare professionals and diverse cultural and religious views. End-of-life decisions should be made according to ethical principles and sound ethical reasoning should be applied in providing

individualized decisions. The four core ethical principles, i.e. autonomy, beneficence, nonmaleficence, and justice, have to be balanced in end-of-life decisions (Gordon, 2002).

Especially in Western countries, the principle of autonomy often overrules other considerations. The definition of autonomy in this context refers to the right of self-determination, exerted by the patient or an authorized surrogate. Self-determination in this context is often reduced to the right to choose one's individual way of dying (Gaertner et al., 2011).

Although this review focuses on autonomy, the three other ethical principles for decision making need to be shortly explained. Beneficence, “to do good”, reflects the healthcare professional's obligation to act for the benefit of the patient. Nonmaleficence, “to do no harm”, is the corollary of beneficence and is the most elemental statement of the goal of healthcare to prevent and alleviate symptoms which cause suffering and even

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more important minimize adverse effects of interventions. Justice refers to the fair and equitable distribution of benefits and burdens in regard to both an individual patient and society. Furthermore, clinicians have to respect the ethnicity, chronological age and religious affiliation in decision making.

The process of decision making at the end of life involves a reasonable number of steps and is based on more than only the individual personal choice.

During the last decades a trend has evolved that the self-determination of the patient is so much emphasized in medicine that it is almost the solitaire argument in debates on end of life decisions. Sometimes there is the impression that autonomy in medicine ethics and increasingly also in legislation is to be identified with a moral right to determine the time of one's death. Such a shortening of the concept of self-determination is a cynical reversal of patient's autonomy.

### 1.1. Providing treatment at the end of life

Frequently, clinicians face controversial discussions about benefit and limitations of medical treatment with patients at the end of their life as a result of expanded therapeutic options (Lindström et al., 2010). Even at a advanced phase of diseases there might remain a plentitude of treatment options to choose from. However, the respect of autonomy cannot ignore the borders of reasonable medical decisions and moral justice since the possibility of a treatment must be weighted against its actual usefulness (Thorns, 2010). Treatment options might be provided but their usefulness for increasing the quality of life or reducing the burden of disease are sometimes not sufficiently evaluated. Therefore, before we confront patients and their relatives with decisions in a critical phase of the disease we have to clarify whether we will be able to prolong the life of the patient and at the same time increase the quality of life. It is useful to discuss this beforehand with colleagues and experts to come to a clear and concise statement for the patient before we discuss a treatment option or even changes in the therapeutic regimen.

### 1.2. Knowledge as the basis of end-of life decisions

Knowledge of diseases, knowledge of disease progression and the knowledge of the burden of decisions for the patient and the relatives is the basis for end-of-life decision making. The relationship between patients, proxies and physicians during end-of-life decision-making is complex and has considerably changed in the last years. Traditionally, paternalism from clinicians has been the source of decisions. This has been criticized in recent years and decision making now is striving for a growing emphasis upon patient's autonomy (Winkler et al., 2012; Billings and Krakauer, 2011). Some patients want to be actively involved in end-of-life decisions and would not leave them to the clinicians (Arora et al., 2005). However, for some patients and relatives end-of-life decisions pose an increased burden. It seems that this group is the majority; they need support by experienced physicians who are able to make personally tailored therapeutic suggestions.

Knowledge of important therapeutic outcome studies is mandatory for end-of-life decisions. However, a number of studies and our own data indicate that knowledge in end-of-life decision is lacking. As an example in a recent study a significant number out of 195 primary care physicians believed against strong evidence from clinical studies that PEG tubes could reduce aspiration pneumonia and improve healing of stress ulcer and nutritional and functional status, and underestimated the 30-day-mortality with a PEG tube (Shega et al., 2003).

In a recent survey in our hospital we have asked physicians and nurses about artificial nutrition and hydration (Unterpaul et al.,

unpublished data, submitted). Within one year we collected questionnaires from 99 nurses and 49 physicians. The main results show a high uncertainty in end of life issues especially in respect to the usefulness of hydration and nutrition for the patient at the end of life.

Our results indicate that religious convictions and putative legal issues restrain physicians from withholding fluids and nutrition (Table 1). Ethical and moral concerns when artificial nutrition and hydration are stopped are common under both physicians and nurses. Furthermore, approximately 60% of physicians fear juridical problems in case they stop hydration and nutrition as an end-of-life decision. And approximately half of the physicians feared that the patient's suffering will increase because of this decision.

Theses answers give not only insight into ethical and moral concerns in end-of-life decisions, but also into the limited knowledge of physicians and healthcare professionals on legal and medical issues. But even existing knowledge is often conflicted by the fear of ethical and emotional as well as legal consequences.

### 1.3. The dialog with the patient

The dialog with the patient is the most important step before treatment. We should know the patient whom we confront with a decision regarding his illness and his life. Knowing includes the life circumstances of our patient, but also his ethical and spital resources and beliefs. It includes the knowledge of his position within the family and the society. We have to know how much information we can deliver without doing any harm. We have to choose the right setting: the patient might want to have family members with him during the dialog. In any case, we should ask the patient whether he wants to have somebody being with him during the dialog without indicating that this is our method for breaking bad news. During this dialog we can evaluate, whether the patient has the ability of decision making on his own. This is necessary since the concept of autonomy depends on the capability of own decision making. On the other hand, this capability is supported by the adequate provision of medical information through the experts. Expert knowledge depends on personal experience and current knowledge of the most relevant scientific results. We must realize the importance of this one essential dialog for end-of life decision making. The content and the way how we present information to the patient largely determine how the patient will decide.

**Table 1**  
Religious and ethical concerns in decision-making.

	Physicians	Nurses
I have religious concerns [%]	6.1	4.1
I have ethical or moral concerns or remorse [%]	32.7	24.5
I fear juridical problems [%]	59.2	49.0
Communication with patients or their relatives is causing me trouble [%]	32.7	48.0
Communication with colleagues of my own profession is difficult for me [%]	4.1	9.2
Interdisciplinary communication with colleagues of other profession is causing me trouble [%]	4.1	21.4
I fear suffering of the patient at its and of life because of my decision [%]	46.9	49.0
I fear increased agitation for my patient at the end of life [%]	42.9	43.9

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