

# **The Final Illness: Decision-making in the Family Unit**

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## **Scientific background**

Greater life expectancy and an aging population cause many people to reach the end of their lives after struggling with a serious illness that affects their physical, psychological, emotional and social functioning. One illness that causes a patient and family much suffering is cancer. Numerous decisions on patient care must be made in the course of the illness. Often, in the final term of a patient's life, the decisions are complex and pose emotional difficulties and ethical dilemmas, nor are they strictly medical, but entail a slew of family, social and moral considerations.

Family members play an important role in assisting patients with personal care, household chores, navigating their way through the medical system, and performing medical-related activities at home. Nevertheless, if a patient is mentally competent, the family theoretically, legally and morally has no place in making medical decisions. Family caregivers have been the subject of a wide-ranging, theoretical and empirical literature which, however, deals mainly with the implications of care on the caregivers themselves (such as burden, the toll on their health etc.). There has been little theoretical discussion of the involvement of family members in decision-making in the life of an ill relative (Cicarelli, 1992) and virtually no empirical study.

The ethical realm, too, assigns no place for family caregivers. The common legal, ethical model in the western world recognizes the right of patients to decide autonomously on the medical treatments they receive. In terms of the pattern of physician-patient relations, the common model today is shared decision-making, which also emphasizes patient autonomy and choice of care.

Family members, despite their great involvement, have no formal-legal standing in decision-making when patients are competent. Should the patient not be competent, a family member is supposed to act as surrogate and this, too, only after legal process according to the Capacity and Guardianship Law of 1962, Patient Rights Act and Dying Patient Act. The autonomist emphasis on abiding by a patient's wishes finds expression in the extensive literature examining the "dangers" of transferring the authority for decision-making to a family member (e.g., incompatibility between the preferences of relative and patient).

The topic of this study emerged in the gap between the significant role of family members in the care of terminal patients and, on the other hand – the legal, ethical expectation that they remain uninvolved in the decisions affecting patient care if the

patient is competent. The main research question concerned the place and function of family members in decision-making, in a relationship shared by patient, family member and physician.

## **Study Methods**

The lack of data and of a solid theory on the place and function of family members in decision-making with respect to competent patients led to the methodology of qualitative research and a quest to develop an inductive theory based on the words of the actors involved – Grounded Theory.

As part of the study, I interviewed 13 families. In each family, I interviewed the patient suffering from metastasized cancer and the relative serving as the main caregiver (one caregiver refused). In two families, an additional relative was interviewed. All the patients interviewed were competent, treated by various oncological services in the hospital and the community (e.g. oncology daycare), and (with one exception) simultaneously treated by a home hospice unit. Most of the patients passed away within a few months of the interview. In addition, to elicit the perception of professionals on the place and role of family members, I interviewed a physician and nurse from the home hospice unit. In total, 29 people were interviewed.

The research tool was a semi-structured in-depth interview seeking to understand the experience of the patients and family members in making decisions concerning the illness. Patients and family members were asked to talk about the illness, its development and the treatment they received. The interviews were conducted separately, except in the case of three families. The physician and nurse were asked to give their point of view of the involvement of family members in decision-making.

The interviews were recorded, transcribed, and analyzed in three stages according to Grounded Theory: open, axial and selective coding. At the end of the analytical process, a theoretical model took shape including the core category of the phenomenon, the main concepts and the dimensions composing them.

## Findings

The study findings elaborate the different forms of decision-making in illness, relating to two spaces: the public space (decisions with the health system) and the private space (within the home), yielding a comprehensive picture of the patterns of action. The main axis emerging in both spaces was the **family unit** acting together.

Patients and family members related to two stages of the time axis: diagnosis and treatment. One important point along the axis of time was the news that there was no cure for the illness ("nothing can be done") and the realization that this was the patient's final illness.

There was considerable change in the comportment of the family unit through the stages of the illness. The diagnostic stage was characterized by a good deal of initiative and activism. Both patient and family were determined to discover what is bothering/ailing the patient and persevere until cancer was diagnosed. At this stage, the patterns of action of the family units were homogeneous. On the other hand, in the treatment stage, families showed variation, indicating four styles of family decision-making:

- 1. Mutual decision-making** – Patient and family exercise "equal weight" in making medical decisions and there is constant negotiation between them. Sometimes the wishes of the relative (to accept treatment) were accepted, sometimes the wishes of the patient (setting boundaries on treatment). In some cases, the decision was made together.
- 2. Delegating decision-making** – The patient "deposits" treatment in the hands of the family, which in turn deposits it in the hands of the physician. The family leads decision-making in the public space (e.g., determining treatment according to the physician's advice in the absence of the patient), but at home the patient's voice is heard more. Generally, the decisions will be in the direction of accepting treatment.
- 3. "The Lost"** – The family does no leading – The patient and family react to the changing states of the illness but do not manage to lead decision-making in the course of the illness. Physicians will decide the direction of care (receiving or stopping treatment).
- 4. Relative autonomy** – The patient leads decision-making about treatment in the public space. However, while the family accepts the patient's opinion in the public space, at home their voice is also heard and they lead decision-making.

Looking at the different decision-making styles above, it emerges that there is variation both in the direction of the decisions made (treatment yes or no) and in the role of leading the decision-making. The knowledge that treatment could not cure the illness was not found to be a distinct factor in a family's comportment. How did the variation in the management of the family units come about? An analysis of the interviews identified three strengths that led to different decision-making styles.

- 1. Conception of death** – Patients and families presented different attitudes to death, sometimes varying within a family itself (e.g., a patient acknowledges death, a family member is in denial), and sometimes changing with the progress of the illness. For instance, when one patient "chose to remain optimistic," i.e. did not acknowledge the approach of death, the decision-making pattern was delegation, the family made the decisions for him, tending towards the acceptance of treatment.
- 2. Family attitude to dependency** – The illness accentuates a patient's dependence on a family member. All the relatives helped the patient, but they differed in their feelings about the help they proffered – from complete mobilization to feeling under duress.

The conception of patient dependency related to the mobilization of family members. For instance, when the family caregiver enlisted totally in the task of care, the patient felt both secure and a sense of communion, and there was cooperation in decision-making (mutual decision-making pattern).

- 3. Suffering** – Some of the families said that there were "respites" in the suffering from the illness: "there are good days and bad days." If patients and family members reported relentless suffering (for example incessant pain), it was accompanied by a pattern of silence and passivity in decision-making ("The Lost" pattern).

To obtain a full picture of the decision making styles, these three strengths – conception of death, dependency and suffering – should be considered in combination. For instance, a relatively autonomous pattern was characterized by a patient's acknowledgment of impending death (conception of death), the absence of a family member at critical moments of treatment (perception of dependency), and intermittent suffering.

## Theoretical Decision-Making Model in End-of-Life Situations

The contribution of this study is the development of an innovative model to understand medical decision-making at the end of life. The data analysis, with the help of Grounded Theory, shows that the main axis for understanding decision-making during the final illness is the family unit. Patients and their families act as **one unit** both in daily life and in the management of the illness, and the action as a family unit impacts both on who will be making the decisions (physician, patient or family member) and on the direction of the decisions (accepting or refusing treatment).

This study is unique in its combination of the three impelling forces. The "place" of the family in each of the forces, and the combined forces, create the style of family decision-making. Suffering may be defined as a quasi-preliminary condition of a family's ability to lead decision-making. If suffering is incessant, that ability becomes paralyzed. If not, the ability is enabled. The two additional strengths can be characterized as moving along two axes: the extent of a patient's preparedness for imminent death, and the dependency created by the illness. On the whole, the axis of preparedness is "led" by the patient. Even if a family member has an opinion on the subject, the decision as to whether or not to talk about it – will be decided by the patient.

The other – vertical – axis is dependency, where the family member takes the lead. If s/he mobilizes to proffer help, i.e., will adjust to the new role of caregiver, the patient will feel that s/he has someone to count on and show more readiness to be dependent and accept the help. If the family member is a physical hands-on helper, but retains his previous family role (e.g., as "husband"), the patient will feel that she has no-one to count on or that she would like more support and help.

According to the model, and the place on the axis of impelling strengths, four family types/patterns are obtained.

When a patient is ready to die and the family enlists totally to care for her/him, a pattern of **mutual** decision-making takes place. If the patient is not ready to die and the family enlists, a pattern of **delegation** will take place, the family making decisions for the patient. If a patient is not ready to die and the family does not enlist, both patient and family will feel **lost**, not leading the decision-making about the illness. The fourth pattern, of **relatively autonomous** decision-making, is found when a patient is ready to accept death and the family is absent at critical moments.

## Discussion

This finding, that patient and family act as **one unit**, is consistent with the Family Systems Theory (Whitchurch and Constantine, 1993). The principle of holism holds that one cannot understand the actions of an individual, the patient, without viewing the other parts of the family. Essential change in the life of one leads to essential change in the life of another.

The findings described above contribute to the existing theoretical knowledge, which does not consider the family's place in the process of patient decision-making; they show that the patient and family are a subsystem, a single unit, in face of the medical system. Moreover, in contrast to the emphasis in the literature on the patterns of decision-making by physician and patient, the study findings reveal that the subsystem of patient and relative impacts essentially on decisions made about the illness.

The forces impelling decision-making – conception of death, attitude to dependency and suffering – may shed light on the gap between the emphasis of western medicine on the patient as an autonomous decision-maker and the picture emerging from the study. For example, the autonomous patient – who is ready to accept impending death, speaks of it freely, and seeks to die in dignity without losing the sense of control over her/his life and body – is considered the "ideal patient." In contrast, the type who is "in denial" about death, for whom the family makes decisions – is mentioned in the literature unfavorably in the context of collective culture.

If the conduct throughout the illness is regarded as a family journey, then family negotiation over decisions and the delegation of decisions by the family may be seen not as a negative, but as a positive, phenomenon. This collective decision-making stems from a real, sincere desire to consider the fears and the reciprocal interests of family members. Consideration of the needs and wishes of family members is part of the autonomous agency of patients. In this, the study findings are consistent with the conception of Relational Autonomy which regards identity and values as embedded in social and family connections, and in contexts with others (Mackenzie and Stoljar, 2000). The willingness of patients in this study (except for those following the pattern of autonomy) to be dependent on others varies out of the fear expressed in the literature about becoming a burden on others (McPherson et al., 2007). This fear is emphasized in the literature due to the identification in the western world of individual autonomy with personality. A blow to one's independence could lead to the feeling that life is no longer worth living.

The study revealed that the sense of dependency or its acceptance appears to take shape and change through the stages of the illness and is based on the family's accumulated experience. Patients fear not the burden of care that will fall on the shoulders of relatives, but the possibility that the relatives will prove unequal to the role and drop it.

The discussion of incessant pain as paralysis in decision-making surprisingly does not receive much mention in the literature. The connection between suffering and important decision-making appears to warrant more in-depth examination. An interesting parallel may be seen in the research of Shafir and others (e.g., Mullainathan & Shafir, 2013) who found that conditions of poverty accompanied by constant survival pressures are detrimental to making informed/wise decisions.

The study findings touch on the philosophical question of whether persons are complete unto themselves (as western individualism would have it) or whether they are whole only as part of a family (according to eastern outlooks). From this study, it seems that towards the end of life, even individuals who behaved autonomously throughout their lives, according to the western perception – are in fact part of a broad family unit.

### **Recommendations for Practice and Policy**

The study findings attest to the gap between the legal approach to the family – having no part in decision-making, and the actual approach on the ground – in fact, playing a part; a gap with which professionals must contend on a daily basis. Apparently, it is necessary to furnish professionals with more tools to cope with, permit and improve the family's presence. One tool that may help is the family meeting/conference on decision-making, guided by a professional.

In addition, there is a need to raise the awareness of professionals as to different family textures, each with different characteristics and warranting a different approach and dialogue. No "one rule" is relevant to all. For instance, one may be able to speak openly of death with some patients, but with others, to strengthen the family connection. Special attention should be devoted to "lost" families, characterized by relatively limited internal strengths and resources. In addition, interventions should be developed to serve the family unit, not merely the needs of a patient or family member.

As regards the ethical questions that arose in the study, there seems to be room to develop general principles to help regulate the place of the family in medical decision-making. These should be compatible with the values of the State of Israel, blending autonomy with family and community values.