

Social Workers' Perspectives on and Participation in Decisions Regarding Life-Sustaining Treatment

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ABSTRACT

Background: The decision-making process regarding life-sustaining treatments (LST) for patients, particularly the elderly, involves ethical and emotional complexities. Social workers, as key members of interdisciplinary healthcare teams, contribute a psychosocial perspective that influences these decisions. However, research on social workers' attitudes, beliefs, and participation in LST decision-making remains limited, despite their significant role in advocating for patient autonomy and family involvement. This study aims to explore social workers' views on LST, factors influencing their attitudes, and their involvement in the decision-making process.

Methods: A cross-sectional survey was conducted with 61 social workers from healthcare facilities across the nation. Participants provided their views on the use of three LSTs—mechanical ventilation, artificial tube feeding, and cardiopulmonary resuscitation (CPR)—in hypothetical scenarios involving an 80-year-old patient with metastatic cancer, irreversible mental illness, or irreversible physical state. Additionally, social workers' perceptions of their role in the decision-making process and their level of involvement in discussions about LST preferences were assessed.

Results: Social workers were more willing to use artificial tube feeding than mechanical ventilation or CPR. Their attitudes toward LST varied depending on the patient's condition, with the least support for LST in metastatic cancer cases. Stronger religious beliefs were associated with a greater inclination to use LST. Social workers expressed strong support for their involvement in LST decisions but reported low levels of active participation in these discussions with patients and families.

Conclusion: Social workers are crucial in the LST decision-making process, particularly in ensuring that patients' wishes and family preferences are considered. However, the study highlights a gap between social workers' emotional preparedness and their active participation in clinical decisions. Further training and integration into interdisciplinary teams are necessary to enhance their involvement and improve patient-centered care in end-of-life decisions.

1. Introduction

Health care professionals, patients, and families face moral conundrums and conflicts when deciding whether to start or continue life-sustaining treatments (LST) for patients of any age, but especially for the elderly (Clarke, Goldstein, & Raffin, 1994; Dorr Goold, Williams, & Arnold, 2000). Using interdisciplinary teams to discuss end-of-life care decisions in general, and life-sustaining treatments in particular, is crucial due to the complexity of these decisions (Joseph & Conrad, 1989; Solomon et al., 1993). These teams typically include a doctor, a nurse, and a social worker, often referred to as supportive care teams, palliative care teams, or symptom assessment teams. Their objective is to support the patient and their family during the challenging LST decision-making process.

Studies have indicated that medical judgments on the use of LST are often more influenced by the age of the patient and the preferences of the doctor than by the patient's preferences or prognosis (Hamel et al., 1999). However, other medical professionals, such as social workers, also play a significant role, as their attitudes and convictions influence end-of-life care decisions. Social workers, in particular, are guided by the biopsychosocial model, which was proposed in the 1970s as an effective and necessary approach to patient care (Engel, 1977). While doctors may lean more towards a traditional biomedical orientation, social workers focus on psychosocial orientations and the broader emotional and social needs of patients and families.

The growing use of interdisciplinary teams highlights the importance of analyzing and understanding the perspectives of different disciplines involved in the end-of-life decision-making process (Shoefield & Amodeo, 1999). Social workers bring a unique perspective that prioritizes patient autonomy, family involvement, and ethical considerations. They are often responsible for ensuring that patients and families are actively engaged in decisions about LST (Coulton, 1990; Csikai, 1999; Lerner, 1994).

A study assessing social workers' attitudes, beliefs, and behavior regarding LST revealed that 71% agreed with the statement that social workers must take charge of involving patients in LST decisions, and 59% believed social workers should ensure family members are included in these discussions (Werner & Carmel, 2001a). Despite the significance of their involvement, research on social workers' attitudes and beliefs regarding LST remains limited. Moreover, there is a need for further investigation into how social workers' perspectives compare to those of other medical professionals involved in the care of patients near the end of life.

The aim of this study is to examine the attitudes, beliefs, and participation of social workers in LST decision-making processes. This research builds on the conceptual model developed by Carmel and Mutran (1997b), which evaluates preferences for LST in elderly individuals and incorporates factors such as fear of dying, professional self-esteem, experience, religiosity, and sociodemographic traits. By focusing on social workers, this study aims to provide insights into their critical role and distinct contributions to end-of-life care decision-making.

2. Methodology

Participants

The study included 61 social workers from major healthcare facilities across the nation. Due to the small number of social workers at each facility, a convenience sampling approach was utilized. While participation was voluntary, approximately one-third of the social workers in these facilities responded to the survey, resulting in a 100% female sample.

Social workers demonstrated higher levels of religiosity, were older, and had more children than their nurse counterparts (Table 1). Additionally, they reported receiving significantly more training for emotional coping with terminally ill patients, though their exposure to such patients was less frequent.

Table 1. Sociodemographic and Professional Characteristics of Social Workers in the Study

Characteristic	Social Workers (n = 61)
Age	42.35 (10.25)
Number of children	4.09 (3.13)
Religious belief (a)	2.61 (1.26)
Number of years in the profession	15.41 (9.01)
Number of years in the unit	6.98 (6.28)
Professional self-esteem (b)	4.22 (0.41)
Daily caring for terminally ill patients (c)	3.13 (0.97)
Training received to deal emotionally with terminally ill patients (c)	3.43 (1.08)

(a) From 1 = no religious belief to 5 = very strong religious belief.

(b) From 1 = not at all true to 5 = very true.

(c) From 1 = never to 5 = all the time.

Measures

Opinions on Life-Sustaining Treatments (LST)

Social workers were asked their opinions on three forms of LST—mechanical ventilation, artificial tube feeding, and cardiopulmonary resuscitation (CPR)—for hypothetical scenarios involving an 80-year-old patient.

The conditions were:

1. Condition A: An 80-year-old patient with metastatic cancer, with some hope for short-term improvements.
2. Condition B: The same patient suffering from an irreversible mental illness like Alzheimer's disease.
3. Condition C: The patient is bedridden, incontinent, and in an irreversible physical state.

Participants rated their willingness to use each LST on a 5-point scale (1 =

"definitely no" to 5 = "definitely yes"). A higher score indicated a stronger willingness to use the treatment. This measure has demonstrated strong conceptual validity and internal consistency in prior research (Carmel, 1998, 1999).

Views on Participation in Decision-Making

Social workers rated their agreement with four statements regarding their involvement in LST decision-making, such as:

1. The social worker must be involved in decisions about continuing or stopping LST.
2. The patient's wishes about LST must be discussed with the social worker.
3. Social workers must involve the patient in treatment decisions.
4. Social workers must involve the patient's family in treatment decisions.

Responses were on a 5-point scale (1 = "strongly disagree" to 5 = "strongly agree"), with a mean score calculated for all items (Cronbach's $\alpha = 0.73$).

Participation in LST Decision-Making

Two questions assessed how often social workers engaged patients and their families about wishes for LST, using a 5-point scale (1 = "never" to 5 = "constantly"). A mean score was calculated for these items (Cronbach's $\alpha = 0.81$).

Fear of Death and Dying

Twelve statements, rated on a 5-point scale (1 = "strongly disagree" to 5 = "strongly agree"), measured fear of death and dying (e.g., "I am afraid of death"). Two indices were computed:

- Fear of Death (Cronbach's $\alpha = 0.80$)
- Fear of Dying (Cronbach's $\alpha = 0.81$)

Higher scores indicated greater fear.

Religiosity

Religiosity was assessed with the question: "How do you rank the strength of your religious belief?" Responses ranged from 1 ("no religious belief") to 5 ("very strong religious belief").

Professional Self-Esteem

The Professional Self-Esteem of Physicians Scale (adapted for social workers) was used, featuring eight items rated on a 5-point scale (1 = "not at all true" to 5 = "very true"). An example item was: "In general, I'm confident that my professional knowledge and skills are on a very high level" (Cronbach's $\alpha = 0.85$).

Procedure

Self-completion questionnaires were distributed to social workers at healthcare facilities. Questionnaires were anonymous, accompanied by a cover letter explaining the study's purpose and emphasizing voluntary participation. Completed surveys

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Statistical Analysis

Multivariate Analysis of Variance (MANOVA): Assessed views on LST for the three hypothetical conditions, controlling for age and religious belief. Multiple Regression Analysis: Explored factors influencing attitudes toward LST in metastatic cancer cases, using variables such as religiosity, self-esteem, fear of death and dying, professional experience, and daily exposure to terminally ill patients. T-tests: Evaluated differences in mean scores for beliefs about involvement in LST decision-making and engagement in the LST process.

3. Results

Differences in Attitudes Regarding the Use of LST for Different Health Conditions

Social workers' attitudes toward the use of life-sustaining therapies (LST) varied based on the specific health conditions described. Social workers showed higher willingness to use artificial tube feeding compared to mechanical ventilation or cardiopulmonary resuscitation (CPR). Across all conditions, social workers were more hesitant to utilize CPR than mechanical ventilation or artificial feeding.

When comparing the three hypothetical scenarios, social workers were least inclined to recommend the use of LST for patients with metastatic cancer. However, their attitudes did not show statistically significant differences between patients with mental impairment and those with metastatic cancer.

Factors Associated with Perceptions of LST Use

A stepwise regression analysis was conducted to identify variables associated with social workers' attitudes toward LST in the metastatic cancer scenario. The results showed that stronger religious beliefs were significantly associated with a greater inclination to use LST ($\beta = .29, p < .01$). Other factors, such as years of experience, fear of death, and professional self-esteem, did not have a statistically significant impact on their preferences.

Social Workers' Views on Participation in the Decision-Making Process

Social workers expressed strong opinions regarding their role in the LST decision-making process. They consistently emphasized the importance of their involvement in decisions about LST, as well as their interactions with patients and their families. Social workers strongly agreed that patients' wishes and family preferences should be integral to decision-making.

Social Workers' Participation in the LST Decision-Making Process

Social workers reported relatively low levels of active participation in discussing LST preferences with patients and their families. A notable percentage (21.3%, $n = 13$ out of 61) of social workers indicated that they were never or very seldom involved in discussing family preferences for LST. Additionally, 29.5% ($n = 18$ out of 61) reported rarely or never asking patients themselves about their wishes regarding LST.

Despite these gaps in active participation, social workers emphasized the importance of emotional training and preparedness in dealing with end-of-life care. Their training in this area contributed to their confidence in addressing the emotional needs of patients and families, though it did not always translate into higher levels of direct involvement in decision-making discussions.

These findings highlight the need for further efforts to integrate social workers into the decision-making processes for LST to align their significant emotional preparation and patient advocacy with active clinical involvement.

4. Discussion

The findings of this study highlight the perspectives, beliefs, and participation of social workers regarding life-sustaining treatment (LST). While the trends in attitudes toward LST varied across different medical conditions, the study revealed that social workers generally reported lower readiness to employ LST, particularly in cases involving metastatic cancer. This finding aligns with previous research, which indicated that healthcare professionals, including social workers, often perceive advanced cancer as presenting significant suffering and reduced quality of life for patients (Foley, 1998). Such beliefs may influence decisions to withhold LST, viewing it as prolonging the suffering of both patients and their families.

In agreement with prior studies (Solomon et al., 1993; Werner & Carmel, 2001b), our analysis showed that social workers were less inclined to support the use of CPR compared to artificial feeding or mechanical ventilation. This difference may stem from professional values and experiences, particularly social workers' emphasis on the psychosocial aspects of patient care. Social workers often prioritize respect for autonomy and self-determination in end-of-life decisions, as highlighted in Csikai's (1999) research on assisted suicide and euthanasia.

Regarding their role in LST decision-making, social workers expressed relatively strong views about the importance of their involvement, particularly in discussions with patients and families. This reflects their training and professional focus on psychosocial care. Social workers' unique skills in addressing emotional and ethical challenges, coupled with their ability to foster communication among interdisciplinary teams, make them indispensable in navigating complex decisions about LST.

Notably, social workers reported greater engagement in conversations with patients and families compared to their counterparts in other healthcare professions. This aligns with the literature, which underscores social workers' role in providing emotional and psychological support to patients and their families (Coulton, 1990). These findings emphasize the value of social workers as facilitators of communication and problem-solving in delicate situations, particularly those involving end-of-life care.

5. Conclusion

End-of-life care decisions involve complex ethical considerations, including

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beneficence, autonomy, and quality of life. Social workers are uniquely positioned to contribute to these decisions through their expertise in addressing psychosocial and emotional aspects of care. The findings of this study underscore the need for educational programs to better equip social workers for their role in end-of-life decision-making.

Future research should further explore the attitudes, beliefs, and practices of social workers regarding end-of-life care, with an emphasis on their interactions with patients and families. Developing training programs that enhance social workers' ability to operate effectively within interdisciplinary teams is essential. Such programs should foster collaboration while emphasizing the unique contributions of social workers in addressing ethical and emotional challenges.

By expanding the involvement of social workers in end-of-life care discussions, healthcare systems can improve communication, reduce stress among patients and families, and ensure that decisions align with patients' values and preferences. Social workers, with their holistic perspective on health, can serve as vital advocates for patient-centered care and as role models for effective collaboration in complex medical decision-making processes.

References

- Antonovsky, A. (1989). The problematic status of the biopsychosocial model. In P. Saladin, H. J. Schaufelberger, & P. Schlappi (Eds.), "Medizin" fuer die Medizin Artz und Zwischen Wissenschaft und Parxis (Medicine for physicians: Between knowledge and practice) (pp. 51–63). Basel and Frankfurt am Main: P. Helbing & Lichtenhahn.
- Blondeau, D., Valois, P., Keyserlingk, E. W., Hebert, M., & Lavoie, M. (1998). Comparison of patients' and health care professionals' attitudes towards advance directives. *Journal of Medical Ethics*, 24, 328–335.
- Carmel, S. (1996). Behavior, attitudes, and expectations regarding the use of life-sustaining treatments among physicians : An exploratory study. *Social Science & Medicine*, 43, 955–965.
- Carmel, S. (1997). The Professional Self-Esteem of Physicians Scale: Structure, properties, and relationship to work outcomes and life satisfaction. *Psychological Reports*, 80, 591–602.
- Carmel, S. (1998). Medical students' attitudes regarding the use of life-sustaining treatments for themselves and for the elderly. *Social Science & Medicine*, 46, 467–474.
- Carmel, S. (1999). Life-sustaining treatments: What doctors do, what they want for themselves and what elderly persons want. *Social Science & Medicine*, 49, 1401–1408.
- Carmel, S., & Mutran, E. (1997a). Wishes regarding the use of life-sustaining treatments among elderly persons: An explanatory model. *Social Science & Medicine*, 45, 1715–1727.
- Carmel, S., & Mutran, E. (1997b). Preferences for different life-sustaining treatments among elderly persons . *Journal of Gerontology*, 52B(2), S97–S102.
- Carmel, S., & Ziedenberg, H. (2000). Nurses' attitudes toward end-of-life of middle aged and old terminally ill patients. In A. Tomer (Ed.), *Death attitudes and the older adult: Theories, concepts, and applications* (pp. 193–210). Philadelphia: Brunner/Mazel.
- Clarke, D. E., Goldstein, M. K., & Raffin, T. A. (1994). Ethical dilemmas in the critically ill elderly. *Clinics in Geriatric Medicine*, 10(1), 91–101.
- Coulton, C. J. (1990). Research in patient and family decision-making regarding life sustaining and long-term care. *Social Work in Health Care*, 15(1), 63–78.
- Coyle, N. (1989). Continuity of care for the cancer patient with chronic pain. *Cancer*, 63,

- 2289–2293.
- Coyle, N., & Ingham, J. (1998). The role of the health care team and case study. In C. K. Cassel (Ed.), *Caring for the dying: Identification and promotion of physician competency* (pp. 47–59). Philadelphia: American Board of Internal Medicine.
- Csikai, E. L. (1999). The role and experience in determining social workers' attitudes toward euthanasia and assisted suicide. *Social Work in Health Care*, 30(1), 75–95.
- Dorr Gould, S., Williams, B., & Arnold, R. M. (2000). Conflicts regarding decisions to limit treatment: A differential diagnosis. *JAMA*, 283, 909–914.
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196, 129–136.
- Foley, K. M. (1998). Palliative medicine, pain control and symptom assessment. In C. K. Cassel (Ed.), *Caring for the dying: Identification and promotion of physician competency* (pp. 11–26). Philadelphia: American Board of Internal Medicine.
- Gillick, M. R., Hesse, K., & Mazzapica, N. (1993). Medical technology at the end of life: What would physicians and nurses want for themselves? *Archives of Internal Medicine*, 153, 2542–2547.
- Hamel, M. B., Teno, J., Goldman, L., Lynn, J., Davis, R. B., Galanos, A. N., Desbiens, N., Connors, A. F., Wenger, N., & Phillips, R. S. (1999). Patient age and decisions to withhold life-sustaining treatments from seriously ill, hospitalized adults. *Annals of Internal Medicine*, 130, 116–125.
- Joseph, M. V., & Conrad, A. P. (1989). Social work influence on interdisciplinary ethical decision-making in health care settings. *Health & Social Work*, 14, 22–30.
- Lerer, G. (1994). Social work role in a case of withdrawal of basic life supports. *Social Work in Health Care*, 20(2), 109–115.
- Mellor, M. J., & Lindeman, D. (1998). The role of the social workers in interdisciplinary geriatric teams. *Journal of Gerontological Social Work*, 30(3/4), 3–7.
- Shoefield, R. F., & Amodeo, M. (1999). Interdisciplinary teams in health care and human services settings. *Health & Social Work*, 24, 210–219.
- Solomon, M. Z., O'Donnell, L., Jennings, B., Guilfooy, V., Wolf, S. M., Nolan, K., Jackson, R., Koch-Weser, D., & Donnelly, S. (1993). Decisions near the end of life: Professional views of life-sustaining treatments. *American Journal of Public Health*, 83, 14–23.
- Werner, P., & Carmel, S. (2001a). End-of-life decision process: The role of social workers in health settings. *Educational Gerontology*, 22, 387–398.
- Werner, P., & Carmel, S. (2001b). Life-sustaining treatment decisions: Health care social workers' attitudes and their correlates. *Journal of Gerontological Social Work*, 34(4), 83–97.