

BIOETHICS NOTES

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"We can have justice whenever those who have not been injured by injustice are as outraged by it as those who have been."
Solon

Ethical Issues in Rehabilitative Interventions during End of Life Care

By Michael Breen

"In end of life care, occupational therapists have many roles. They educate patients and families to decrease stress and fatigue and enhance pain management techniques. They promote function and minimize caregiver burden through problem-solving and recommendation of appropriate adaptive equipment and technological devices. Clearly, occupational therapy enhances quality of life, even in the presence of life-threatening illness." *Mary Egan*

Mary is an eighty year-old who lives independently and has a poor cardiac prognosis with an ejection fraction of 10%, requires oxygen and is significantly deconditioned. During a recent hospitalization, she had planned on discharge home. Unfortunately, Mary realized this would be unsafe due to increased and unexpected difficulties with self-care, and concerns for her safety during ambulation. Mary came to this realization while discussing long-term health and quality of life issues with the occupational and physical therapists at the hospital. Her new goals include a brief rehabilitation or skilled nursing stay to learn the skills necessary for her future safety and well-being. Mary now understands this will require learning new strategies for ambulation and other self-care skills so that she can eventually transition home safely.

Too often the use of rehabilitation strategies, including occupational and physical therapy assessments and treatment regimens, are considered inappropriate for patients during end of life care. However, there are many benefits of occupational and physical therapy for patients like Mary. Individualized treatment plans can help increase comfort, maintain or improve mobility, and decrease pain during this difficult transition. Occupational therapists teach patients about ergonomic principles and the effective use of adaptive equipment to help the patient reduce or eliminate pain during daily

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activity. This leads to a better quality of life and a greater sense of independence.

Therapists use their skills and knowledge to integrate the patient and patient's family with specific therapies that can improve the quality of life. The goal of the therapist is to identify how Mary would like to spend her remaining time and energy, and offer strategies for Mary to achieve these goals. Enabling patients to continue their normal daily routines greatly improves their sense of well-being and quality of life. Egan (2003) describes the process as "affirming life, preparing for death." In our example, Mary seeks to affirm life by returning home to live independently. In addition, occupational therapists can also ease the burden on caregivers through problem-solving and the use of simple adaptive equipment such as shoe-horns, sock aides, reachers, adaptive utensils, and devices to assist mobility.

Research confirms the need for continued studies in the area of rehabilitation in order to help justify interventions and clarify benefits that allow for more informed decision making (Sackley 2009). Bello-Haas (2002) suggests that rehabilitation in end of life care should: 1) improve the quality of life through physical

and psychosocial interventions, in order to reduce the gap between a patient's expectations and hopes and actual experiences, and 2) assist the person to live as fully as possible within the limitations of their disease. These two goals aspire to the ethical goal of beneficence, doing good.

Ensuring that Mary is able to accomplish her stated goals and anticipated outcome is important. Mary's sense of well-being is a primary focus of care, not simply exercise capacity. Recent studies have been mixed in their conclusions. Parsons and King-VanVlack (2009) showed improvement in exercise but no change in quality of life. De Backer (2008) showed improvement in exercise as well as quality of life. McCormick (2009) found improvement in symptoms and quality of life with no claims of physiological improvement. Continued studies are required to help clarify these differences in outcomes. Additional benefits were also identified by these studies. Rehabilitation programs helped identify previously unknown co-morbidities which, if undetected, would have reduced the patient's quality of life. In addition, rehabilitation programs also effected continuing dialogue and discussion between family and physicians during end of life care.

Rehabilitative interventions at the end of life involve two important ethical issues, justice and beneficence. It is clear that rehabilitation during end of life care can be beneficial but it is often difficult to determine the value of intervention. In patients with end stage disease, rehabilitation can be justified if it improves the patient's quality of life and health outcomes. It is not sufficient to justify rehabilitation based simply on physiologic improvements and esoteric goals such as strength, endurance and cardiopulmonary function. It is equally as important to consider the value of these treatments for the patient's overall quality of life, functional physiological improvement, mortality rate and health outcome. In our example, Mary would not benefit from working toward elbow flexor strengthening goals nor aggressive endurance goals. Mary would benefit most from improved ambulatory safety and self-care strategies in order to regain her independence and assist her transition home.

These decisions weigh heavily on our collective role of social responsibility. The appropriate intervention for each patient improves patient satisfaction and helps to reduce the "gap between a patients expectations... and actual experience" (Bello-Haas). This ensures necessary and effective intervention strategies and avoids costly errors. McCormick emphasized the importance of dialogue and discussion between family and rehabilitation professionals. This is the most effective avenue for reducing this gap and helping the patient to

affirm life and prepare for death. Healthcare workers can facilitate this by encouraging patients to take part in, and direct, their own care. With the patient's goals defined, occupational and physical therapists can evaluate and offer those strategies best suited to meet those ends.

Respectfully Submitted,
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