Chapter 58
Telemedically Augmented Palliative Care:
Empowerment for Patients With Advanced Cancer and Their Family Caregivers

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ABSTRACT

Patients with advanced cancer have a substantial symptom burden, which deteriorates their quality of life. Palliative care improves well-being of patients and their family caregivers. Within the scope of a controlled pilot study, a user-friendly telepresence system is developed, which enables patients and family caregivers to send a direct request to a palliative care team. Additionally, a specially tailored database is developed, which contains up to date patient information. Twenty patients with advanced non-small cell lung cancer are consecutively assigned in a control and an intervention group. The intervention group receives the telemedically augmented care, whereas the control group receives standard care. The primary goal of this chapter is to determine the usability and feasibility; the secondary goal is the assessment of the intervention's impact on quality of life and the number of unscheduled hospital admissions. To sum up, telemedically supported ambulatory palliative care may synergistically help to improve safety and quality of life.

INTRODUCTION

In the context of this telemedical project, the quality of life (QoL) of patients with end-stage lung cancer and their family caregivers will be improved through the possibility of obtaining medical advice 24 hours a day by means of a telemedical system. The system will link them to a palliative care team with the click of a button. During daytime, this team usually consists of several nurses and physicians, as well as of one dietician, one psychologist, one pastor, one social worker and volunteers. Furthermore, a specially tailored database including up-to date important patient information, which can be fed by both the palliative care team and the patients themselves, will be developed. Thus, we hope to improve not solely the QoL of these patients, but also the QoL of their family caregivers.

Although the overall cancer mortality is decreasing, 20,000 people still died of cancer in Austria in 2010 [1]. Utilizing palliative care is a only feasible alternative to respond to urgent needs of chronically sick people by improve their wellbeing and quality of life [2].

Most patients with chronically deteriorating incurable disease prefer to spend their last days of life at home [3]. Mobile hospice teams are a well-accepted alternative to provide medical support outside hospitals. A mobile hospice team supports the family caregivers, who are entrusted with the highest amount of the patient's daily care. The term family caregiver is used for all non-professional caregivers, such as family, friends and neighbors. The mobile hospice team consists, depending on individual requirements, of physicians, nurses, social workers, pastors and volunteers. It works together closely with general practitioners, hospitals and home nursing services and offers support in legal issues and organizational problems. The aim is to sustain QoL of patients and their family caregivers.

Generally, mobile hospice care is well accepted by patients and family caregivers. Nevertheless, the major problem is the general scarcity of mobile hospice teams available. Resources are usually not sufficient to manage acute medical problems, especially after hours. If a patient encounters medical problems during the night, usually the emergency service is called and patients are frequently admitted to a hospital. This happens mostly because of lacking information on history and current development of the patient's medical problems.

The primary aim of this project is to improve the QoL of patients and family caregivers by reducing stress and increasing safety. The secondary aim of this study is to reduce the heavy costs due to unnecessary hospital admissions.

Our system proposed comprises an integrated telemedical system, including a telepresence system and a database. Patients and family caregivers will have the possibility of obtaining medical advice 24 hours a day by telemedical support. Due to the organizational structures in the General Hospital of Vienna, they have the possibility to talk to a pastor/ social worker/ psychologist/ dietician only during daytime and if available. The telemedical system will enable patients and their family caregivers to videoconference with the Unit of Palliative Care (Department of Internal Medicine, General Hospital of Vienna), providing professional medical care and psychosocial support. Additionally, a database will be made available to document the patient's condition. This database will not only be fed by medical professionals, but also by patients and family caregivers themselves to document the patient's individual needs. Thus, QoL of these patients and their family caregivers will be improved through the possibility to send a medical request at any time, to receive medical advice quickly and by the reduction of hospital admissions.

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