

Supportive Care: The Patient's Care?

Louis Caze

Louis Caze CEO centre Louis Caze Paris, France

Introduction

What is supportive care? Support care means all care and support that can be offered to a person suffering from cancer, alongside specific treatments to cure his disease such as chemotherapy, radiotherapy and surgery. They aim to reduce the impact of disease and treatment. For this, a team of professionals specialized in very different fields put their skills available to patients to help them cope with this difficult time. The support can be offered care during and after treatment of the disease but also when the cancer treatments have no effect. They adapt to the needs of patients and their families. What needs do they meet? The disease affects all aspects of daily life. The needs that may occur are numerous.

Background of the Research

Most patients have families that are providing some level of care and support. In the case of older adults and people with chronic disabilities of all ages, this “informal care” can be substantial in scope, intensity, and duration. Family caregiving raises safety issues in two ways that should concern nurses in all settings. First, caregivers are sometimes referred to as “secondary patients,” who need and deserve protection and guidance. Research supporting this caregiver-as-client perspective focuses on ways to protect family caregivers’ health and safety, because their caregiving demands place them at high risk for injury and adverse events. Second, family caregivers are unpaid providers who often need help to learn how to become competent, safe volunteer workers who can better protect their family members (i.e., the care recipients) from harm.

This chapter summarizes patient safety and quality evidence from both of these perspectives. The focus is on the adult caregiver who provides care and support primarily for adults with chronic illnesses and chronic health problems. The focus is not on those with developmental disabilities. In the first section, we discuss the evidence for protecting the caregiver from harm.

The second section addresses research aimed at protecting the care recipient from an ill-prepared family caregiver.

The terms family caregiver and informal caregiver refer to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care. Recent surveys estimate there are 44 million caregivers over the age of 18 years (approximately one in every five adults).¹ The economic value of their unpaid work has been estimated at \$257 billion in 2000 dollars.² Most caregivers are women who handle time-consuming and difficult tasks like personal care.³ But at least 40 percent of caregivers are men,³ a growing trend demonstrated by a 50 percent increase in male caregivers between 1984 and 1994.⁴ These male caregivers are becoming more involved in complex tasks like managing finances and arranging care, as well as direct assistance with more personal care.⁵ Nurses are likely to see many of these caregivers, although many of them will not identify themselves as a caregiver.

Those caring for someone 50 years or older are 47 years old—on average—and working at least part-time.¹ If they are providing care to an elder who is 65 years or older, they are, on average, 63 years old themselves and caring for a spouse; one-third of these caregivers are in fair to poor health themselves.⁶ In many cases, they are alone in this work. About two out of three older care recipients get help from only one unpaid caregiver.⁷ In the last decade, the proportion of older persons with disabilities who rely solely on family care has increased dramatically—nearly two-thirds of older adults who need help get no help from formal sources.