

Chapter 8

Supporting Family–Based Care for Aged Patients with Chronic Illness

Lemai Nguyen
Deakin University, Australia

ABSTRACT

Family carers play an important role in care for aged patients with chronic illness, particularly in home and community settings. The information needs of these family carers and their patients are poorly understood and current health information systems do not adequately support their needs. This chapter describes current models in understanding patient and family carer information needs and analyses technology solutions in a new field of consumer health informatics. The analysis shows that current technology solutions in consumer health informatics fail to effectively support aged people in their own management of chronic illness and as well failing to support their family carers. The chapter also identifies key research issues in developing technologies that support aged patients and family carers in chronic illness management.

INTRODUCTION

About 13 per cent of our Australian population is aged 65 years or older (Department for Health and Ageing, 2008). This is projected to rise to 18 per cent by 2021 and to 26 per cent (around 7 million people) in 2051. Healthy ageing and aged care have increasingly become an important, national issue. There is a wide range of social, health and economic aspects in ageing and aged care. One

of many challenging aspects is how to cope with and manage the increasing incidence of chronic illness, for example depression, diabetes, heart disease, asthma, and various types of cancer. Morbidity and mortality related to major chronic diseases increase after 65 years of age (AIHW, 2006). Chronic illness, if not well managed, can become an expensive challenge (WHO, 2002). For optimum chronic illness management, an integrated hospital and home continuous care programme is required (ITTA-eHealth, 2004).

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Hospital care involves high costs and is an inefficient use of care resources compared with preventative, primary or community care. Family carers play an important role in reducing costs associated with aged patients with chronic illness. Better understanding of and addressing the information needs of family carers is expected to provide significant benefits in providing chronic illness care for aged patients (Clayton, Butow, & Tattersall, 2005). Family carers not only provide home-based continuous care for aged patients but also often act as their proxy information seeker (Williamson & Asla, 2009). In addition to having a rich understanding of the patient-specific care needs, the family carer also has his/her own needs, for example, access to patient's health information, knowledge about the patient's illness and care instructions, and how to cope with emotions and stress associated with care (Docherty, et al., 2008). Inclusion of the information needs and information behaviours of the family carers in health information strategies and systems can be expected to provide significant benefits.

Consumer health informatics is a relatively new field that aims to understand and address the information needs of patients and their families, and empower them in health care planning, delivery and decision making (Altinkemer, De, & Ozdemir, 2006; Hersey, Matheson, & Lohr,

1997). Based on an analysis of the information needs of patients and family carers, especially in the context of home-based aged care, this chapter reviews and discusses current technologies used in consumer health informatics. A research programme will be described to support family-based care by addressing the information needs of aged patients and family carers.

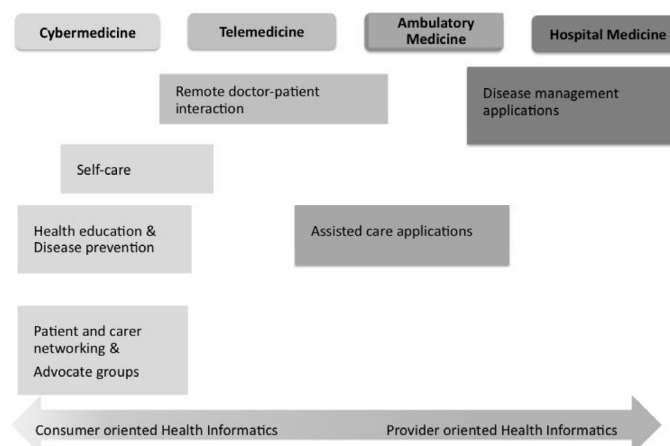
INFORMATION NEEDS OF AGED PATIENTS WITH CHRONIC ILLNESS AND THEIR CARERS

What is Consumer Health Informatics?

Traditional health informatics, also referred to as medical informatics, tends to focus on the information needs of the healthcare provider, as opposed to the healthcare consumer (see Figure 1). Consumer health informatics can be described as “the study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumers” (Ferguson, 1993).

Eysenbach (2000, p. 1715) offers a more comprehensive definition using five dimensions:

Figure 1. Customer health informatics: focus of new medical informatics (adapted from Eysenbach, 2000)



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