Chapter V

Chronic Disease Registers in Primary Healthcare

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ABSTRACT

Systematic care of patients with chronic diseases needs to be underpinned by information systems such as disease registers. Their primary function is to facilitate structured care of patients attending services—supporting identification of patients at risk, structured preventive care and provision of care according to guidelines, and supporting recall of patients for planned visits. In Australia general practitioners using division-based diabetes registers are more likely to provide patient care that adhered to evidence-based guidelines. Critical data issues include privacy, ownership, compatability, and capture as part of normal clinical care and quality.

INTRODUCTION

Chronic diseases account for over 70% of the burden of disease in countries such as Australia (Mathers, Vos, & Stevenson, 1999), and more than one in four problems managed by general practitioners relate to one or more of these chronic conditions (Australian Institute of Health and Welfare [AIHW], 2002). Systematic team care of patients with chronic diseases such as diabetes and cardiovascular disease is associated with improved health outcomes (Dunn & Pickering, 1998; Wagner, 1998; World Health Organization [WHO], 2001). This needs to be underpinned by information systems that assist with recall and audit according to evidence-based guidelines.

In many countries, organizations of primary-care services have been established at local or district levels. In Australia, the Divisions of General Practice have played a key role in supporting general practices to provide more systematic care through disseminating evidence-based guidelines, educating general practitioners and consumers, supporting shared care and self-management education, providing allied health services, and coordinating local registers for recall and audit. The authors have been involved in one widely implemented computer-based register system that has demonstrated improvements in the quality of care.

BACKGROUND

Functions

Disease registers have a variety of purposes ranging from facilitating longitudinal research to providing epidemiological surveillance. Their primary function in primary healthcare is to facilitate the structured care of patients attending services: supporting the identification of patients at risk, structured preventive care, the provision of care according to guidelines, and the recall of patients for planned visits.

Location

Registers may be located at the service (e.g., within a general practice) or at the healthcare organization level (e.g., a diabetes centre or the Division of General Practice). Registers within practices or services have the advantage of ease of data capture, avoiding problems of data transfer. Registers at the district or regional level held by a specialized service or primary-healthcare organization have greater capacity for analysis and are able to monitor the care provided by a multidisciplinary team across different services.

Data

Registers contain individual-identifying information, such as basic demographic profiles for recall purposes, together with information about the process and outcomes of care. This information needs to be standardized to allow comparison using nationally accepted units of measurement and frequencies for routine testing and recall. In Australia, standardized minimum data sets have been developed based on evidence-based guidelines for the management of diabetes or cardiovascular disease (National Health Data Committee, 2003a, 2003b), overseen by committees representative of primary-care providers, nongovernment organizations (NGOs), specialist providers, government agencies, and consumers.

Data Capture

Patient data may be recorded and captured in a variety of ways. Historically, data have been recorded on forms or copies of patient-held records,

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