Editorial

Joav Merrick

Chronic illness, disease and impairment: living longer, living well

DOI 10.1515/ijdhd-2015-0006

Introduction

Chronic illness, disease and impairment have a few points of entry. The first is children who survive childhood with acute disease, but now have a chronic illness, and the other spectrum is adults who were healthy and now have a chronic illness or disease that modern medicine cannot cure.

Looking back on history and especially medical history, children born with significant congenital anomalies, genetic and metabolic diseases or disabilities perished at an early age, and very few survived into adolescence and even fewer into adulthood. Congenital heart disease, major disorders in metabolism, cancer, cystic fibrosis and many other diseases were fatal.

Today with advances in medical knowledge and technology, many of these patients now live longer and sometimes even close to the average life expectancy. In this way, childhood diseases have become lifelong diseases. Health care providers in adult medicine such as family practitioners, internists, cardiologists and so on have now to deal with individuals suffering from unfamiliar diseases that were previously seen only in pediatric care. Today, many pediatricians all over the world find themselves caring for forty year olds with, for example, congenital heart disease or cystic fibrosis because health care transition to adult care has not been possible [1, 2].

The term “medical home” was first used by the American Academy of Pediatrics in 1967 to describe the concept of a single centralized source of care and medical records for children with special health care needs [3] and later, in the 1990s, advocating for pediatricians to transition their chronically ill patients to adult health care. Many health care systems around the world are still struggling with these issues, and various models have emerged [1, 2, 4].

As part of “the new morbidity” in both pediatric and adult medicine, chronic illness has emerged as a major health concern in recent decades. Both professionals and also the general population are increasingly focused not simply on living longer, but on maintaining or even improving their capacity to live well with a good quality of life over their entire lifespan.

Institute of Medicine report 2012

The Centers for Disease Control and Prevention (CDC) and the nonprofit Arthritis Foundation in the United States recently sought assistance from the Institute of Medicine (IOM) to help identify public health actions to reduce disability and improve the function and quality of life for people living with chronic illness [5].

Chronic illness is becoming an economic burden for society and a major contributor to health care costs. The medical care costs of people with chronic illnesses represent 75% of the $2 trillion in United States annual health care spending [5].

The committee behind the report [5] identified nine conditions as examples: arthritis, cancer survivorship, chronic pain, dementia, depression, type 2 diabetes, post-traumatic disabling conditions, schizophrenia and vision and hearing loss. The committee recommended that the Department of Health and Human Services support states in developing comprehensive, population-based strategic plans with specific goals, objectives, actions, timeframes and resources that focus on managing chronic illness, including community-based efforts to address the health and social needs of people living with chronic illness and experiencing disparities in health outcomes. The committee had the following recommendations:

– Expand surveillance and mitigation programs to the widest possible range of chronic illnesses. Having better data will inform planning, development, implementation and evaluation of public health policies, programs and community-based interventions for individuals living with chronic illness.

– Surveillance techniques that are likely to capture multiple chronic conditions effectively. As one example, the CDC should conduct longitudinal evaluations – which
can shed light on hidden relationships – to identify and quantify the effects of various risk factors that could predict how a given illness will progress over time and how having a single chronic disease increases the odds of suffering from additional ailments.

- The CDC should support expanded use of new and emerging economic methods, such as cost-effectiveness techniques, in making policy decisions that promote living well with chronic illness.
- The CDC should pilot test a “Health in All Policies” approach on a set of major federal legislation, regulations and policies and evaluate the framework’s ability to improve quality of life and physical function for people living with chronic illness. The “Health in All Policies” approach rests on the assumption that health is fundamental to every sector of the economy and that every policy – large and small – should take into consideration its effect on health.
- The CDC should routinely examine and adjust its policies to ensure that community-based services for people living with chronic disease reflect the priorities embodied in health care and insurance reform legislation.

**A United Kingdom strategy**

A report from NHS East Sussex [6] looked at a 5-year strategy for existing and future health, social care and housing support needs of adults in later life and their carers. The mission should be to

- Enable people to live active lives with dignity and independence
- Improve quality of life and physical and mental wellbeing
- Prioritize prevention, early detection and treatment of ill health
- Support access to a range of good quality health care and housing support services that provide good value for money.

The aim of the mission is to 1) develop and improve the range of community services to promote independence and well being; 2) develop and improve accommodation options, with more community-based services and supported housing; 3) develop and improve the range of community services for those who have urgent, transitional or ongoing complex needs; and 4) develop and improve the range of services for people with dementia and functional mental health issues.

The guiding principles of service and care should be [6]

- That services are in place for each stage of the care pathway
- Prevention and opportunities to support healthy lifestyles are embedded into services
- Make services more personalized and easier to access
- Value for money and efficiency within available resources
- More cross agency investments and integrated and co-located health, social care and housing support services by supporting market development and being open to new ways of working with both current and new partners
- Improving health outcomes and reducing health inequalities
- Reduce dependence on hospital and long-term care by moving care closer to home, making it easier to access and continuing the shift from residential to community-based services
- To treat people with respect and dignity
- Promote independence to deliver increased life expectancy
- Support people to take control of their own health, social care and housing support needs and commissioning high quality personalized services
- Reduce inequalities for potentially excluded and seldom heard groups and people in deprived areas
- Support market development and joint commissioning of services by health, social care and housing
- To aim to meet both current and future needs and demand

**Conclusions**

Modern medicine has been able to cure acute disease and unable to cure chronic illness, but indeed has prolonged life for people who suffer chronic illness. This has resulted in a large number of people with chronic illness who are unable to work and are an economic burden on the health care system and society.

The life and well-being of people living with chronic illnesses has not been given the attention it deserves by health care funders, health systems, policy makers and public health programs and agencies. We therefore now need to take a new look at this topic and develop programs and services that will help these people maintain a better quality of life, with some being able to contribute to the workforce despite their illness and provide a better quality of life living with chronic disease. This presents a real challenge for public health.
Author contributions: The author has accepted responsibility for the entire content of this submitted manuscript and approved submission.

Research funding: None declared.

Employment or leadership: None declared.

Honorarium: None declared.

Competing interests: The funding organization(s) played no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the report for publication.

References


*Corresponding author: Professor Joav Merrick, MD, MMedSci, DMSc, Medical Director, Health Services, Division for Intellectual and Developmental Disabilities, Ministry of Social Affairs and Social Services, PO Box 1260, 91012 Jerusalem, Israel, E-mail: jmerrick@zahav.net.il