



Ongoing Behavioral Management of Common Chronic Illnesses

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“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick.”

Sontag, 1979, p. 3

Introduction

Teaching medical students about medical care for patients with chronic illnesses tends to lead to confusion, bewilderment, and anger in at least a few of them. Most medical students have images of their future professional lives as young physicians, dressed in white coats that flutter while running through empty hallways late at night—heading for the emergency room where they will perform heroic, complex medical miracles, after which the patient will go home the next morning, completely recovered. To many of them, it comes as quite a shock to learn about the “epidemiological transition”: the shift from “cure” to “care” and the shift from acute illness to chronic disease (Harper & Armelagos, 2010). These changes in the focus

of medical care have many implications for all involved: patients, their partners, physicians, other healthcare professionals, society, and psychologists who teach medical students or provide clinical care for patients with chronic somatic disorders in a behavioral medicine setting.

In this chapter we will outline some of the implications of this epidemiological transition for medical care and for behavioral medicine and specifically review and discuss the following:

- The characterization of “chronic illness” and its implications for the contributions that medical care and behavioral medicine offer to the well-being of patients with those illnesses
- Some theoretical models that are instrumental and important for providing medical and behavioral medicine care to persons with chronic physical illness
- Self-management of chronic illness
- The empirical literature on the ongoing behavioral management of six major chronic somatic illnesses, namely, asthma, COPD, cancer, cardiovascular disorders (in particular, heart failure), diabetes mellitus, and rheumatoid arthritis

The chapter will conclude with some suggestions that may help strengthen research on ongoing behavioral management of patients with chronic illnesses.

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Chronic Illness

The word “chronic” comes from the Greek “chronos,” meaning “time”; in Greek, “chronikos” means “during a long period of time.” The element of time, therefore, is a core concept in most descriptions of chronic illness. There is no generally accepted definition of “chronic illness.” Verbrugge and Patrick provide a definition of “chronic conditions” that encompasses the core elements of most other descriptions of the concept:

long-term diseases, injuries with long sequelae, and enduring structural, sensory, and communication abnormalities. They are physical or mental (cognitive and emotional) in nature, and their onset time ranges from before birth to late in life. Their defining aspect is duration. Once they are past certain symptomatic or diagnostic thresholds, chronic conditions are essentially permanent features for the rest of life. Medical and personal regimens can sometimes control but can rarely cure them. (Verbrugge & Patrick, 1995, p. 173)

“Most people reading this chapter will probably die of a chronic disease” – this is how Burish and Bradley (1983, p. 3) start the introduction to their book on coping with chronic disease. Some 30 years later, this statement is more true than ever. Public health researchers predict that by 2020, the chronic illness conditions of cancer, ischemic heart disease (including cerebrovascular disease), and chronic obstructive pulmonary disease (COPD) will make up the top of the list of diseases causing morbidity (Lopez, Mathers, et al., 2006).

Two myths deserve attention in the context of chronic (somatic) disorders. First, it is too simplistic to assume that medical care has contributed greatly to the increased longevity in industrialized societies. Bunker (2001) debunks this myth by demonstrating how “age-adjusted death rates were reported to be greater in countries with greater numbers of doctors, and presumably with more medical care [...] death rates for diseases amenable to treatment were reported to be greatest in areas with the most medical care resources” (p. 1260). Behavioral scientists who claim that behavioral interventions for high-risk health behavior produce meaningful gains in life

expectancy create myths as well: “with about a quarter of the population smoking, the population as a whole would gain about one and a half years if every smoker quit” (Bunker, 2001, p. 1262). Rose’s “prevention paradox” seems to be valid here as well (John, 2011): “Population strategies which focus on reducing the risk of those already at low or moderate risk will often be more effective than strategies which focus on “high risk” individuals at improving population health” (John, p. 250). Morbidity and mortality are part and parcel of the “condition humaine” (Murray & Lopez, 1997).

Theoretical Models Regarding Behavioral Medicine Interventions in Chronic Illness

Various models have been developed, and tested, regarding medical and behavioral medicine management of people with chronic physical illnesses. Two models in particular stand out as they have been instrumental in the development of theoretical and empirical work: (1) the Common Sense Model, and (2) the Chronic Care Model.

In the *Common Sense Model*, the central tenet pertains to the making sense of physical sensations by people and the consequent steps in this process of sense making (Leventhal, Brissette, & Leventhal, 2003). When a person perceives a physical sensation, the person is assumed to be motivated to minimize the health-related risks and reduce the health threats in a fashion that is consistent with the representations s/he has about an illness. People form representations of an illness based on their knowledge of an illness, its representation in media (TV, Newspapers, Movies etc.), and encounters with the medical system. It is irrelevant whether these representations, or illness perceptions, are medically “correct” (assuming one could define what “correct” is). What *is* relevant is that these perceptions guide the response of patients to illnesses and, thereby, their self-management and outcome (see Fig. 30.1). Systematic reviews and meta-analyses

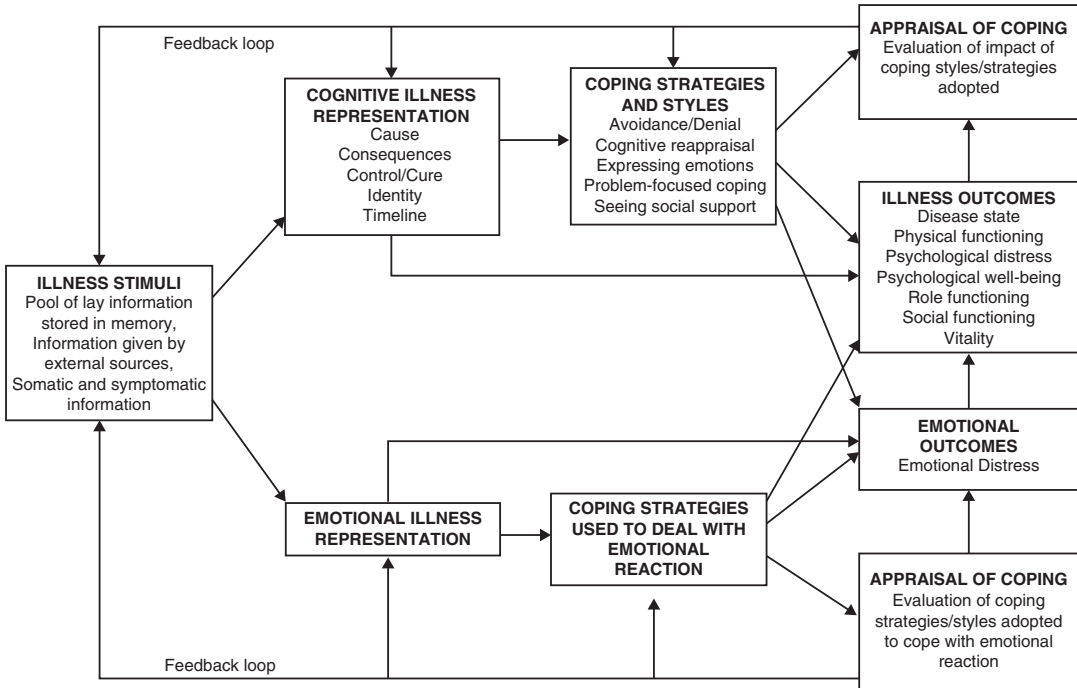


Fig. 30.1 The common sense model (From Hagger & Orbell, 2003)

of empirical work employing the Common Sense Model show how illness perceptions are powerful predictors of outcome in patients with chronic illnesses (Hagger & Orbell, 2003; Kaptein, Scharloo, et al., 2003). At least as important is the evidence about the effectiveness of interventions in the context of the Common Sense Model. If illness perceptions determine outcome, then changing illness perceptions should lead to changes (i.e., improvements) in self-management and, therefore, in outcome. A number of intervention studies do support this statement. For example, Jansen, Heijmans, Rijken, and Kaptein (2011) describe an intervention program and its initial encouraging results in patients with end-stage renal disease and their partners, based on the Common Sense Model. Skinner et al. (2011) report the positive effects of a self-management intervention in patients with diabetes, where the intervention lead to improvements in illness perceptions, which in turn were associated with positive changes in clinical characteristics.

As demonstrated in Fig. 30.1, contextual factors are not explicitly integrated into the Common Sense Model. These issues are part of the second model, the *Chronic Care Model* (Fisher, Brownson, et al., 2007; www.improving-chroniccare.org).

Here, self-management – a core concept in the Common Sense Model – is embedded into a social context and characteristics of the health system. The elements “community, resources, and policies” and “health systems, organization of healthcare” pertain to organizational characteristics of care delivery, where “practitioners have relationships to larger health care organizations and community resources that can support and enhance high quality chronic illness care” (Wagner, 2010, p. S637). Primary care (or family medicine, general practice) is conducive in achieving these conditions. Also, these organizational structures have implications for the education of healthcare professionals (e.g., Bodenheimer, Lorig, et al., 2002).

As Wagner and colleagues have noted, self-management interventions “generally emphasize the patient’s crucial role in maintaining health and function and the importance of setting goals, establishing action plans, identifying barriers, and solving problems to overcome barriers” (Wagner, Austin, et al., 2001, p. 74). These authors also importantly point out that “with a few exceptions, the tested interventions do not include long-term support for patient self-management or efforts to engage the primary care team” (Wagner, Austin, et al., 2001, p. 74). Other elements in the Chronic Care Model outlined in Fig. 30.2, such as delivery system designs, decision support, and clinical information systems, are aspects which help achieve productive interactions and improved outcomes.

A systematic literature review of applications of the Chronic Care Model in various chronic physical illnesses leads to modest optimism (Minkman, Ahaus, & Huijsman, 2007): “some evidence has been found that implementing interventions based on the Chronic Care Model improves performance (of the health care system and its professionals)” (p. 96). In their meta-

analysis of interventions to improve care for chronic illnesses, Tsai, Morton, Mangione, and Keeler (2005) review 112 studies on asthma, congestive heart failure, depression, and diabetes in the context of the Chronic Care Model. They conclude that “... interventions that contain 1 or more elements of the Chronic Care Model can improve outcomes and processes for several chronic illnesses of interest to managed care organizations” (p. 487). Additional information on theoretical models and their application to the (self-) management of patients with chronic physical illnesses is provided by Newman and colleagues (Newman, Steed, & Mulligan, 2009).

The Common Sense Model and the Chronic Care Model – and related models, cf. Newman, Steed, and Mulligan, (2009) – point at the increasingly central position of the patient in modern medical care for people with chronic illnesses. Figure 30.3 illustrates this evolution.

The concepts of “self-management” and “disease management” at the top right-hand corner of Fig. 30.3 roughly reflect the Common Sense Model and the Chronic Care Model, respectively.

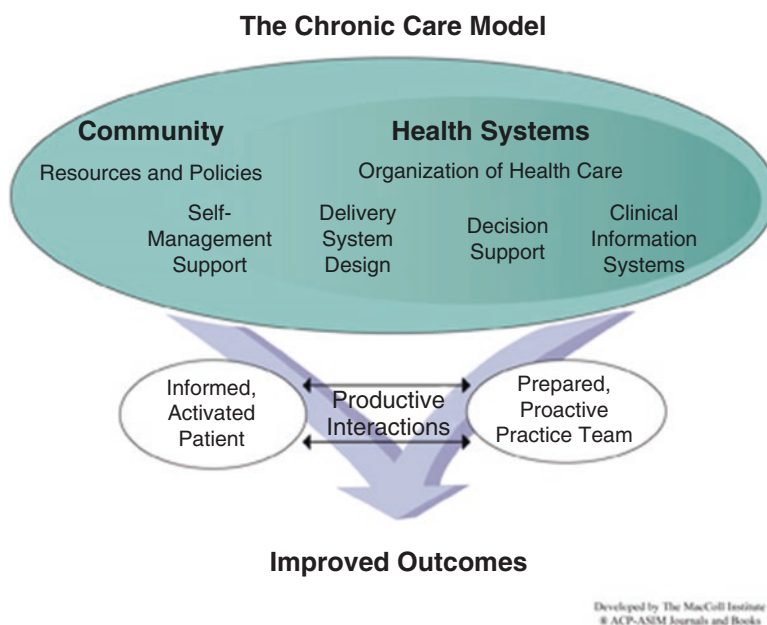


Fig. 30.2 The Chronic Care Model (Fisher, Brownson, et al., 2007)

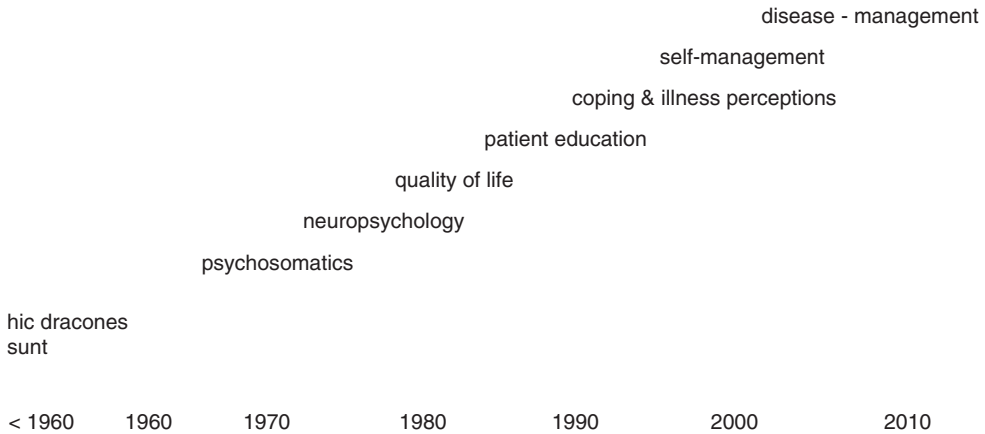


Fig. 30.3 Power to the patient: the increasing involvement of patients in medical care (Kaptein, Scharloo, et al., 2009)

Some 60 years ago, patients were quite often perceived as merely passive recipients of and in medical care. At best, their responses to illness were examined and conceptualized in the context of psychopathology, which it was thought contributed to the somatic disorder. Increasingly, patients have become more active partners in their interactions with healthcare professionals. Disease management is the most recent concept in this evolution. It is defined as “an approach to patient care that emphasizes coordinated, comprehensive care along the continuum of disease and across health care delivery systems – patient counseling and education, coordination, and standardization are key components” (Peytremann – Brideveaux, Staeger, et al., 2008, p. 434).

Self-management is a key component in the management of chronic illness. We might estimate that an “average” patient will have direct face-to-face contact with a health professional in the healthcare system about 1 hour per year, which means that during the other 8759 h of the year, the patient must manage his or her illness without healthcare providers. Self-management is defined by Barlow and colleagues as:

... the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s

condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. (Barlow, Wright, et al., 2002, p. 178)

Self-management skills are diverse and include such behaviors as gathering information, managing medication, symptoms and psychological consequences, adjusting lifestyle, mobilizing and drawing on social support, and communicating effectively (Barlow, Wright, et al., 2002).

In this part of the chapter, we have outlined some key theoretical concepts and models that have been employed in the chronic illness field. We now move on to self-management interventions and applications, focusing on ongoing efforts from healthcare providers and patients to continue self-management behavior in the long term.

Behavioral Management of Common Chronic Illnesses

As suggested in Fig. 30.2, self-management and disease management imply that patients with chronic physical illnesses are encouraged and empowered to self-manage their medical condition, in collaboration with people in their social environment, healthcare providers, and society.

Our focus in the current chapter is on *ongoing* behavioral management and its effect on various outcome measures. We will explore this in the context of six specific chronic illnesses, selected due to their high prevalence and the availability of a fairly substantive body of knowledge on the effects of self-management in patients with these illnesses: asthma; chronic obstructive pulmonary disease (COPD); cancer; cardiovascular disease, in particular heart failure; diabetes mellitus; and rheumatoid arthritis. Research was selected for inclusion here based on its empirical and theoretical contributions.

Asthma

Behavioral medicine management for patients with asthma aims at controlling and reducing the effects of the illness in the daily lives of patients. School absenteeism, absence from work, limitations of daily activities, hospitalization, and even death are consequences of asthma. Via managing medication, based on adequate symptom perception, quality medical care, and adjusting one's lifestyle, most patients are able to limit the impact of asthma in their daily lives (Kaptein & Creer, 2004). Cochrane reviews (e.g., Gibson, Powell, et al., 2002; McLean, Chandler, et al., 2010) and systematic reviews (e.g., Bravata, Gienger, et al., 2009) provide empirical support for this statement. The area of self-management in asthma is relatively well developed. Empirical studies on the effects of ongoing support for behavioral management of asthma are discussed below.

The promotion of self-management throughout the illness trajectory is nowadays considered one of the cornerstones of asthma treatment (BTS, 2008; GINA, 2010; NHLBI, 2007). Emphasizing the long-term character of care for patients with asthma, practitioners are advised to review patients' asthma control and to reinforce knowledge and self-management skills at every opportunity (NHLBI, 2007). A Cochrane review showed that for adult patients with asthma, the combination of regular review of asthma control

by a healthcare provider with the promotion of self-monitoring of symptoms and/or of peak expiratory volume (PEF) and the use of a personalized written action plan for exacerbations was more beneficial than either of these initiatives alone (Gibson, Powell, et al., 2002). These combined interventions were associated with a reduction in hospitalizations, ER and unscheduled doctor visits, days lost from work due to asthma, episodes of nocturnal asthma, and improvement in quality of life. Although the evidence regarding the effectiveness of these interventions is quite consistent, recent surveys indicate many GPs do not yet appear to incorporate them on a regular basis (Boulet, Devlin, & O'Donnell, 2011).

School-based educational programs for children are an alternative route to provide asthma education. The advantage of these programs is that they provide education to children in a setting in which they are accustomed to receiving instruction and emphasize teaching children how to manage asthma rather than relying on parents to do so (Coffman, Cabana, & Yelin, 2009). Typically these programs are efficacious in improving knowledge, self-efficacy in managing asthma, and self-management behaviors. The effects of these educational programs for children with asthma on health outcomes, however, are mixed (Coffman, Cabana, & Yelin, 2009).

Bruzzese and colleagues (2011) present results from an intensive school-based program, targeting not only urban adolescents but also their medical care providers. Three group educational sessions about asthma were organized. In addition, students received individual coaching sessions once a week for 5 weeks, in which skills for asthma management were taught and reinforced. Students were coached in overcoming barriers to optimal self-management and were encouraged to visit their healthcare provider for evaluation and treatment (health educators offered to accompany students to the medical visit). Students' medical care providers were informed that their patients, participating in the program, would be referred to them and received instructions on how to complete a personalized action plan together with their patient. Participants

were followed for 12 months. Every 2 months health outcomes (daily/nocturnal symptoms, school absenteeism, days with activity restrictions, and quality of life) were reviewed. In addition, self-management, medication adherence, use of the written action plan, and urgent healthcare use were assessed at 6 and 12 months. Results after 1 year following the intervention showed that this comprehensive approach had led to an increase in steps taken by the students to prevent asthma symptoms and higher self-efficacy to control asthma. Students in the intervention arm used their personalized action plan more frequently. Nocturnal symptoms, asthma-related school absenteeism, and days with activity restrictions were also consistently lower in the experimental condition. Finally, there was a significant reduction in healthcare use, while the number of acute medical visits, emergency department visits, and hospitalizations were all lower for students in the experimental condition. The authors themselves acknowledge the self-report nature of major outcome measures as a study limitation.

Community health programs have been developed to intervene in the living environment for patients with asthma. Repeated home visits provide the opportunity to tailor the intervention to the specific conditions of each patient and to monitor progress. Usually, the interventions focus on patient education regarding asthma triggers and ways to decrease or avoid triggers. Additionally, patients are often provided with tools or resources to decrease the impact of triggers (e.g., mattress or pillow encasements, vacuums, air filters, rodent traps, or high-quality door mats). A review of the outcomes of community health worker-delivered home-based interventions showed positive effects of these interventions on asthma symptoms, daily activity limitations, and emergency care use (Postma, Karr, & Kieckhefer, 2009). Changes in preventive (asthma trigger reduction) behaviors, hypothesized to mediate the effects of the intervention, were observed although this was largely dependent on the provision of resources as part of the intervention. Combining community health interventions with traditional clinic-based asthma

education may yield a long-term added effect on symptoms and trigger prevention actions (such as vacuuming the child's bedroom, washing sheets, and avoiding indoor smoking (Krieger, Takaro, et al., 2009)).

Interventions that offer remote support to patients with asthma have been introduced over the last decade. McLean and coworkers performed an extensive review study on the effects of tele-healthcare for asthma patients (McLean, Chandler, et al., 2010). Tele-healthcare interventions were defined as those programs that enable remote delivery of patient-centered care (e.g., by telephone, text message, video, Internet), facilitate timely access to health advice and medications, prompt self-monitoring and medication compliance, and educate patients on trigger avoidance. Twenty-one randomized controlled studies were identified that compared tele-healthcare interventions with care as usual. The authors concluded that, on average, there were no clinically meaningful differences between the control group and the experimental condition with regard to quality of life and emergency visits over 12 months. However, it appears that for patients with poorly controlled asthma, tele-healthcare interventions reduce the risk of hospitalization and, as a consequence, have a beneficial effect on healthcare costs. Additionally, tele-healthcare interventions enable healthcare providers to review more patients in the same time span than during face-to-face consultations. There was no evidence that the delivery of remote healthcare increased chances of adverse events.

One example of a successful tele-healthcare intervention was performed by van der Meer and colleagues (van der Meer, Bakker, et al., 2009). In this study an Internet-based self-management program for patients with asthma was compared to usual care. In addition to the usual physician care, patients in the experimental condition monitored their asthma symptoms weekly by completing an online questionnaire. Patients received feedback with advice on how to adjust their medication (increase or decrease). This feedback was generated automatically according to a predefined algorithm and treatment plan.

During the study, patients were provided with asthma specific information and had the opportunity to contact a respiratory nurse specialist online. Additionally, patients were provided with two group-based self-management education sessions, aiming to increase knowledge, skills, and self-efficacy. After 1 year, patients in the internet group showed greater improvement in self-reported quality of life and asthma control than patients in the control group. Also, patients in the online group had experienced an increase in symptom-free days and showed a modest improvement in lung function. In sum, weekly online self-monitoring and subsequent treatment adjustment appears to be an efficient long-term intervention to improve asthma control, particularly for patients who report difficulty in controlling their asthma (van der Meer, Bakker, et al., 2009). Similar results were reported by Krishna, Francisco, Balas, König, Graff, and Madsen (2003).

Estes discusses the Chronic Care Model with “asthma as an exemplar” (Estes, 2011) –illustrating the potential relevance of the model for asthma. Fisher et al. (2009) report on the effects of ongoing support of self-management behaviors in a predominantly African American population, where mothers of children with asthma were encouraged to adopt an action plan about self-management by “asthma coaches.” These coaches aimed at providing the mothers with a regular visit to encourage them to adhere to the action plan. Rates of hospitalization were reduced significantly in the children with asthma in this condition of the randomized controlled study.

In summary, empirical evidence suggests there are positive outcomes of ongoing behavioral support to improve self-management in patients with asthma.

Chronic Obstructive Pulmonary Disease (COPD)

Chronic obstructive pulmonary disease (COPD) represents a major chronic illness in western societies, with developing countries picking up rapidly. COPD will be the third leading cause of

death in the next decade (Lopez, Mathers, et al., 2006). The irreversible destruction of lung tissue, caused mainly by smoking tobacco, is associated with high levels of restrictions in daily activities, psychological problems (depression, anxiety), social isolation, high rates of use of healthcare services, forced retirement, and increased levels of mortality. Pharmacological treatment is helpful in reducing breathlessness, cough, and fatigue. However, progress in pharmacological management of patients with COPD is underwhelming. Behavioral interventions focus on pulmonary rehabilitation, self-management, smoking cessation and support, and disease management (for systematic review, Cochrane review, and meta-analysis, see Adams, Smith, et al., 2007; Effing, Monninkhof, et al., 2007; Peytremann – Brideveaux, Staeger, et al., 2008). The Cochrane review on self-management education in COPD concludes that “it is likely that self-management education is associated with no indications for detrimental effects in other outcome parameters. This would in itself already be enough reason for recommending self-management education in COPD. However, because of heterogeneity in interventions, study populations, follow-up time, and outcome measures, data are still insufficient to formulate clear recommendations regarding the form and contents of self-management education programmes in COPD.” (Effing, Monninkhof, et al., 2007, p. 2). The systematic review and meta-analysis conclude that “COPD disease-management programs modestly improved exercise capacity, health-related quality of life, and hospital admissions, but not all-cause mortality” (Peytremann – Brideveaux, Staeger, et al., 2008, p. 433).

As is the case in so many studies in so many medical conditions, there is a dearth of studies where *ongoing* interventions of self-management support are part of the experimental design, assessment, and outcome. Two early and two recent studies are worth briefly reviewing here. Güell et al. (2000) examined the short- and long-term effects of an ongoing pulmonary rehabilitation (PR) program in COPD patients. In a controlled design, 30 patients received PR care as usual, while 30 additional patients received PR

care plus ongoing self-management support. This support consisted of 3 months with outpatient breathing retraining and physiotherapy, 3 months of daily supervised exercise, and 6 months of weekly supervised breathing exercises which included relaxation techniques and “educational sessions.” On outcome measures such as dyspnea perception, fatigue, and emotional functioning, self-reported improvements were observed in the self-management group compared to the control group, even after a 2-year follow-up. Improvements were also found on the 6-min walk test.

Case management comprised the content of ongoing support in a study where a clinical nurse specialist and a social worker were part of an experimental condition in a controlled study design (Poole, Chase, et al., 2001). Both professionals saw the patients in their homes on a regular basis for a year. The patients ($n = 16$) were encouraged to discuss any problem they had with managing their illness, and they were provided with a problem plan and received education about how to self-manage exacerbations. Family members were encouraged to become involved with the intervention components. Weekly telephone calls and home visits every month were part of the ongoing interventions and support. The control group received care as usual, i.e., without case management. The support intervention led to a reduction in the number of bed days, while in both conditions the number of hospital admissions was reduced.

Adams et al. (2007) reviewed the use of the Chronic Care Model (CCM) in COPD prevention and management and concluded that “... patients with COPD who received interventions with 2 or more CCM components had lower rates of hospitalizations and emergency/unscheduled visits and a shorter length of stay compared with control groups” (p. 551). Two studies published following this review provide further evidence for this conclusion. In a study by Lawlor et al. (2009), long-term follow-up education, telephone support, and rapid future access to respiratory outpatient clinics led to significant reductions in emergency department visits and hospital admissions. In a qualitative Australian study, community nurses who provided ongoing behavioral

medicine support to COPD patients reported changes in their views on their contribution to the care for the patients: “... this included a shift from a fatalistic, prescriptive, biomedical approach to a primary health care approach characterized by empathy, consultation, facilitation and a holistic focus” (Robinson, Courtney-Pratt, et al., 2008, p. 371).

In a recent review of behavioral interventions in COPD, we concluded that COPD is no longer an orphan disease with regard to self-management interventions (Fischer, Scharloo, et al., 2007; Kaptein, Scharloo, et al., 2009; Scharloo, Fischer, et al., 2012). Given the increasing amount of research examining the effects of ongoing self-management support in COPD, our cautious optimism seems to be upheld. Yet more rigorous research is required to further identify and elucidate the effective characteristics and aspects of self-management support. In this way we may be able to design more effective interventions to improve quality of life in people with COPD.

Cancer

Given the high incidence and prevalence of cancer, and the relatively long research tradition regarding behavioral interventions in this area (with or without ongoing support and intervention), there exists a relatively substantial body of empirical studies which has examined ongoing support and interventions. McCorkle et al. (2011) recently employed the Chronic Care Model as a guiding principle to review 16 studies on self-management, enabling and empowering patients to live with cancer as a chronic illness. Below we briefly discuss three of these 16 studies, in which the design encompassed ongoing (elements of) self-management interventions.

Bakitas et al. (2009) examined the effects of a nurse-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer. In a randomized controlled trial format, advance practice nurses ran four weekly educational sessions with monthly follow-up until death or study completion. The content of the intervention was “educate, nurture,

advise, before life ends [ENABLE],” and this led to significant improvements in quality of life and mood compared to the care as usual condition.

Miaskowski et al. (2004) examined the effects of the PRO-SELF Pain Control Program on pain intensity and quality of analgesic prescription in a randomized clinical trial design in patients with bone metastases. Specially trained oncology nurses delivered the intervention: pain was discussed from various perspectives (i.e., knowledge, self-management, medication, communicating with health providers). The nurses contacted patients in the experimental group by phone, and pain and its management were reviewed. Home visits were also part of the program. In the control group, patient received phone calls from the research nurses as well, but not home visits. Results showed significant health gains on self-reported pain levels and adequacy of pain medication prescription in the intervention group compared to the control group.

While the Miaskowski et al. study focused on individual patients in individual sessions, a study by Northouse, Kershaw, Mood, and Schafenacker (2005) had the dyad patient – family caregiver as the unit of intervention. Patients with breast cancer and their family caregiver were randomized in the experimental FOCUS condition or in the care as usual condition. FOCUS is the acronym for the elements of the program: family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management. The intervention comprised of three home visits by a trained nurse, spaced 1 month apart, with a booster phase 6 months later, two prearranged follow-up phone calls to both the patient and family caregiver. Results showed improvements in psychological outcomes, in patients and their family caregivers in the FOCUS compared to the control condition, and these positive results remained apparent after 3 months but not 6 months.

A UK review on cancer follow-up (Davies & Bateup, 2011) is also worth mentioning, not because it focuses on self-management per se, but because it adds the perspective of health service research. The review focuses on cancer survivors (“someone who is living with or beyond

cancer,” p. 143) and follow-up medical care. The authors conclude that their review highlights “... a shift towards patient empowerment via individualized and group education programmes amid an increasing survivors’ ability to better manage their condition and the effects of treatment, allowing for self-referral or rapid access to health services when needed. The role of specialist nurses as key facilitators of supportive aftercare is emphasized, as is the move towards technology-based aftercare in the form of telephone or web-based services” (p. 142).

Cardiovascular Disorders: Heart Failure

An exhaustive review of ongoing support and intervention in the area of cardiovascular disease would merit a separate chapter in itself. Therefore, we have selected one diagnostic category within the class of cardiovascular disorders, associated with a major burden of disease and many self-management skills, namely, heart failure.

In a systematic review of randomized controlled studies, Jovicic, Holroyd-Leduc, and Straus (2006) examined six studies on self-management interventions and health outcomes in patients with heart failure. A later review by Yehle and Plake (2010) identified 12 studies, nine of which are randomized controlled trials. Two conclusions can be drawn from these reviews: (1) self-management in patients with heart failure leads to reductions in all-cause hospital readmissions and heart failure readmissions, and (2) self-management in these patients improves self-efficacy, which may be associated with positive outcomes on clinical variables. In intervention studies in which self-efficacy is the central dependent outcome variable, the reviewers found no dose-response effect, even following long-term interventions with ongoing support of self-management.

Jaarsma et al.’s (1999) study involved heart failure patients who received intensive, systematic, and planned education from a study nurse. Visits started in the hospital and continued in the home 3 and 6 months following discharge. Patients also received telephone calls in their

homes, and during these calls and the visits self-management behavior was discussed and encouraged. Generic self-care behavior and heart failure-specific self-care behavior improved in the intervention group compared to the care as usual group. Use of healthcare resources was not different across the groups.

Krumholz et al. (2002) employed a similar randomized design of education and support intervention in patients with heart failure. An experienced cardiac nurse provided the patients with educational lessons and material. Telemonitoring was used by the nurse who phoned patients once a week for 4 weeks, then biweekly for 8 weeks, and monthly for the total intervention period of 1 year. Patients in the care as usual condition did not receive the calls. The study found that patients in the intervention group showed improvements in clinical outcomes, such as reductions in healthcare costs and hospital readmission and increased survival.

As with ongoing support for self-management behaviors in other chronic illnesses, internet-based interventions have been applied in patients with heart failure. One such application is System Providing Patients Access to Records Online (SPPARO), which was developed by Ross, Moore, Earnest, Wittevrongel, and Lin (2004). SPPARO is specialized software that consists of a patient-accessible web-based electronic medical record, an educational guide, and a message system for communication between the patient and hospital staff. Access to medical records may educate, engage, empower, and assist patients in the self-management of cardiovascular diseases. The authors conducted a randomized controlled trial in 107 patients with heart failure to assess SPPARO. Patients in the intervention ($n = 54$) and control group ($n = 53$) received questionnaires on health status, patient satisfaction, and self-reported compliance at baseline, 6 months, and 12 months. Use of SPPARO was highest during the first 3 months after enrolment and then gradually declined. The intervention group sent more messages to the practice than the control group. There was a trend toward self-efficacy improvement and patient satisfaction with doctor-patient communication in the intervention group.

The authors conclude that patient access to medical records may offer modest benefits. However, only a small sample size was used, which limited the power to detect effects of the intervention.

Diabetes Mellitus

As emphasized by Fisher, Thorpe, DeVellis, and DeVellis (2007), living with diabetes mellitus is a lifelong situation patients must face and cope with. At the same time, they may feel somewhat comforted by the fact that support for ongoing self-management of this prevalent chronic physical illness seems to be one of the most developed. The relatively high prevalence of the illness and the major role of the patient him/herself in managing the daily tasks of monitoring and managing blood glucose levels may have contributed to this situation. In addition, patient organizations in the diabetes area were relatively quick in understanding the great importance of helping patients manage their illness themselves. Given this situation, it is not surprising that excellent systematic reviews, meta-analyses, and Cochrane reviews are available to allow conclusions to be drawn about the current state of knowledge regarding ongoing self-management support for people with diabetes.

A 2009 Cochrane review by Deakin and colleagues (2009) of group-based training for self-management in patients with diabetes mellitus type 2 concluded rather spectacularly that “Adults with type 2 diabetes who have participated in group-based training programmes show improved diabetes control (fasting blood glucose and glycated haemoglobin) and knowledge of diabetes in the short (four to six months) and longer-term (12 to 14 months) whilst also having a reduced need for diabetes medication. There is also some evidence that group-based education programmes may reduce blood pressure and body weight, and increase self-empowerment, quality of life, self-management skills and treatment satisfaction” (p. 2).

In her 2008 review of the effects of community-based peer support groups, ongoing home support via telephone, and eHealth, Clark concludes that

“... evidence supports the effectiveness of self-management education in individuals with diabetes, particularly in the short term ... however, reviews have demonstrated sharp declines in benefits only a few months after interventions ended ... overall, self-management education is most likely to be successful when it is part of a comprehensive and coordinated approach to diabetes care” (Clark, 2008, pp. 118–119).

Davis, O’Toole, Brownson, Llanos, and Fisher (2007) explored the contributions of community health workers (CHWs) on diabetes self-management. The authors collected data from logs completed by CHWs which described mode, place, type, duration, and focus of individual contact between the type 2 diabetes patient and the CHW. Data from semi-structured interviews with patients ($n = 47$, purposeful sample) were also used in the analysis. The CHWs logged 1859 individual contacts, in which they reported using the telephone 82% of the time, while face-to-face contact was used in 15% of the contacts. Most contacts were initiated by the CHWs (89%), and the median time of the contact was approximately 6 min. CHWs reported providing assistance (38% of the time) and teaching or practicing a skill (29% of the time) as the main focus of these individual contacts. The interviews with patients revealed that community health workers were monitoring the status of the patients and encouraging self-management through ongoing follow-up and support.

The authors conclude that community health workers make important contributions in teaching skills, helping with problem solving, motivation, and ongoing follow-up and support. CHWs were perceived by the patients as more accessible and helpful in explaining how to carry out self-management and more attentive than health professionals, family, and friends.

However, results should be treated cautiously given that the study involved a small and purposeful sample of type 2 diabetes patients, limiting its external validity.

Gambling and Long (2006) explored patients’ perceptions of movement through the trans-theoretical stages of change model (TTM) within a diabetes tele-care intervention. Case study data

($n = 25$) were drawn from a wider randomized controlled trial in which the effectiveness of proactive call center-based treatment support for patients with type 2 diabetes was explored. Twenty-five patients participated in in-depth post-trial semi-structured interviews. Patients were categorized in four groups based on their pre- and post-HbA1c results: good controllers that remained good ($n = 7$), poor controllers who remained poor ($n = 6$), poor controllers who became good ($n = 10$), and good controllers who became poor ($n = 2$). The “good to good” patients were all at the maintenance stage (having changed behavior for over 6 months) and only tweaked their management approach practices. The “poor to poor” group was at the pre-contemplation stage (no intention to take action within the next 6 months) and either did not apply advice provided, did not apply it long enough, or were unsuccessful in their attempts. The “poor to good” group tended to display strong experiential processes in terms of consciousness and dramatic relief. In this group, the tele-care workers became the first or major point of advice and support. The “good to poor” group only consisted of two patients who made some behavioral changes but did not fully understand the implications of poor control and/or did not make changes consistently. It is clear that each group had different processes over time and in different ways.

Qualitative studies may help shed light on patients’ views regarding self-management. Danish researchers explored diabetes patients’ views about their experiences with managing their illness, following self-management training. The results are important in the context of this chapter: patients said they needed specific support in the daily responsibility of managing diet, exercise, medication, and blood glucose monitoring (Rosenbek Minet, Lønving, et al., 2011). In a similar vein, a study by van Bastelaar, Pouwer, Cuijpers, Riper, and Snoek (2011) identified symptoms of depression and diabetes-specific distress as barriers to adequate self-management. A web-based cognitive behavioral intervention was developed to address these issues.

Increasingly, nurses and physicians acknowledge the great relevance and importance of

(ongoing) self-management in patients with diabetes (Dancer & Courtney, 2010, for nurse practitioners; Yu & Beresford, 2010, for (family) physicians). Both papers underline the point made by Fisher, Brownson, O'Toole, Shetty, Anwuri, and Glasgow (2005), "beyond the self in self-management" (p. 1524): contextual factors are at least as important as patient-related variables in encouraging and maintaining self-management behavior in patients with diabetes (or for any chronic illness, for that matter). This focus on contextual factors also minimizes the likelihood of blaming the patient, as their life worlds are revealed in greater depth.

Rheumatic Illnesses

The benefits of short-term programs promoting exercise, physical activity, and self-management regarding rheumatoid arthritis (RA) outcomes have been consistently demonstrated (Hurkmans, van der Giesen, et al., 2009; Iversen, Hammond, & Betteridge, 2010). However, as in other chronic illnesses, studies on the effectiveness of approaches to provide ongoing follow-up and support for promoting sustained disease management are scarce.

Three main areas have been investigated in the research to date, namely, interactive online environments for peer group support, community-deliverable exercise programs, and consolidation after rehabilitation.

Interactive Online Environments for Peer Group Support

One small qualitative study on the effect of participating in an online support group (van Uden-Kraan, Drossaert, et al., 2008) found positive empowering outcomes experienced by the participants, such as being better informed, feeling confident in their relationship with physicians, treatment and social environment, acceptance of the disease, optimism and control, self-esteem and social well-being, and collective action. Respondents (10 breast cancer, 11 fibromyalgia, and 11 arthritis) were highly active users, mostly female ($n = 30$), relatively young (43 years), with

a mean disease duration of 2 years. The study was replicated in a larger sample ($n = 528$, 23% arthritis) with the same results, and no significant differences were observed between the diagnostic groups with regard to empowering outcomes (van Uden – Kraan, Drossaert, et al., 2009). The authors suggest that online support groups are a useful resource for patients and that healthcare providers should thus acquaint their patients with the existence of these groups. However, their studies also revealed that online support groups for arthritis are the least active when compared to the other diagnostic groups.

Community-Deliverable Exercise Programs

Arthritis-appropriate interventions identified by the Centers for Disease Control and Prevention (CDC) for use in public health settings in the USA include three physical activity and three self-management interventions (Brady, Jernick, et al., 2009). Of these the Arthritis Foundation Aquatic Program (AFAP, www.arthritis.org/aquatic-program.php), the Arthritis Foundation Exercise Program (AFEP/PACE, www.arthritis.org/af-exercise-program.php), and the Project Enhance Fitness (www.projectenhance.org) can be offered on an ongoing basis. The Arthritis Foundation offers practical help (training for instructors, implementation guidelines, marketing, connection to other programs, educational resources) for lay people from a community wanting to start a group.

With respect to other countries, ongoing exercise programs for patients with arthritis are generally offered through websites from (local) Arthritis Foundation offices (e.g., the UK, Australia, New Zealand, Germany) or patient alliances (e.g., UK, Netherlands). A recent meta-analysis suggests that (short-term) community deliverable exercise significantly improves pain and physical function in arthritis and other rheumatic diseases (Kelley, Kelley, et al., 2011).

Consolidation After Rehabilitation

Based on the trans-theoretical model of behavioral change, the Community Rehabilitation Network (CRN, Hong Kong) developed a three-

phase self-management service which places more emphasis on the process of self-help and support services to assist patients with RA (Siu & Chui, 2004).

In the orientation (pre-contemplation) phase of the program (2–4 weeks duration), patients are provided with disease-related information and information on community resources. Patients are encouraged to (re-)mobilize their peer and social support network and alleviate their sense of helplessness in facing the disease, and readiness for developing effective ways of coping with illness is promoted. In the intervention (contemplation) phase (2–3 months duration), patients are encouraged to participate in three standardized intervention programs, including a stress management group, a self-management course, and a water exercise class. In the consolidation phase (6 months), patients are assisted to habituate self-management behavior and are stimulated to maintain a supportive social network. The services provided in this stage include regular reunion meetings and volunteer training programs to equip participants with further knowledge in disease management and available community resources as well as communication and peer counseling skills training to prepare them to conduct home and hospital visits to peers. In addition to the program elements, informal activities are organized throughout the three phases to help expand social support among participants and provide mutual support. Activities include social and recreational activities such as camping and outings, hospital visit/home visit by groups of two or three volunteers in the company of a staff member, and visits to centers offering consultations, educational talks and seminars, and community resources.

Compared to the control group (patients who declined after the orientation phase of the program), the 29 patients in the treatment group (self-) reported significantly greater improvement at the end of the consolidation phase. They improved significantly in self-efficacy, exercise behavior, and cognitive symptom management and made less use of community services for tangible help and more use of education service/support groups for health problems and of organized

exercise programs. Their communication with their physician also improved. However, the study did not find significant differences in change scores for health outcomes such as pain and physical discomfort, energy and fatigue, self-rated health, and healthcare utilization between the intervention and the control groups.

For the treatment group, it was noted that more changes occurred in the consolidation phase, when the CRN adopted a facilitator role rather than an interventionist role, suggesting that the development of social networks plays an important part not only in sustaining the effects from the initial program but also in producing further improvements.

Discussion

There are a number of key themes that arise from the selective review we have presented in this chapter concerning ongoing behavioral intervention and support in patients with six major chronic physical illnesses. Self-management is associated with positive outcomes in patients with chronic physical illness. Self-management impacts on two major categories of outcome: it reduces use of healthcare services in some illnesses, and it improves quality of life in virtually all patients (see Newman, Steed, Mulligan, 2009, and the systematic reviews described in our chapter). In some cases, self-management may be as effective as some medical treatments. Much of the research (but not all) is guided by theoretical models on self-management, behavioral interventions, healthcare services, and medicine. Humanistic motives seem to be important in these scientific efforts, as are issues regarding financial costs of healthcare.

It is surprising that the “acute care model” still dominates not only medical care but self-management research and practice as well. Self-management research tends to employ the classic randomized trial, in which patients are allocated randomly to an intervention or a control condition. The control condition is generally care as usual, while the intervention is generally a 6-week self-management program.

Studies typically assess changes in a number of outcomes in both groups after a relatively short period of time and based on the results conclude that the patients in the intervention groups do better in some of these outcome measures. However, these improvements are not always maintained, nor frequently followed for longer periods of time. Some research indicates that 1 year later, patients are back to baseline levels of outcome measures. We are surprised that researchers (ourselves included) adopt an episodic care model in patients with lifelong illnesses, assessing the effects of intervention efforts after only 3-month “follow-up” (at best). Studies where effects of interventions in self-management behavior are assessed after much longer, and perhaps more relevant, periods are scarce. Researchers understand immediately why this is: research grants usually run for no longer than 3 or 4 years. Within this context, even a 1-year follow-up is difficult in such a limited period of research time. In addition, patients move to other cities, get bored by our ongoing self-management support effort, or die. Additionally, we know surprisingly little about patients’ wishes regarding ongoing self-management support (cf., Devitt, Hatton, et al., 2010; Mann, & Gooberman – Hill, 2011; Tiemensma, Kaptein, et al., 2011). Healthcare providers may become annoyed by requests from researchers for filling out questionnaires and selecting and including patients in studies – although there are exceptions (e.g., Khunti, Gray, et al., 2012).

However, the research does suggest that the Chronic Care Model, and other theoretical models about human health and illness behavior, seem to be helpful in designing research about ongoing support in self-management of chronically ill persons. This is valuable for future research. Nurse practitioners, research nurses, and specialized nurses are a group of professionals who are providing much of the self-management training and material. Perhaps surprisingly, physiotherapists are conspicuously absent in studies on delivering self-management guidance and skills. Physicians also do not seem to spend enough time and

care regarding discussing self-management with their patients, perhaps due to the time scarcity in healthcare organizations. Ironically, the same might be said for psychologists. Expert patients do not yet appear to represent a major category of trainers. This option deserves further study, in our opinion (cf., the Chronic Disease Self-Management Program, e.g., Ghorob, Vivas, et al., 2011; Ritter, Lee, & Lorig, 2011; Willis, Robinson, et al., 2011). In male veteran patients with diabetes, for instance, a reciprocal peer support program produced positive outcomes on biomedical outcome measures and self-reported diabetes social support (cf., Fisher, Boothroyd, et al., 2012). Web-based interventions are increasingly being employed in self-management interventions, and these are naturally appealing as methods to be used in this context: they can, once developed, be employed easily, cheaply, and at a time and place chosen by and convenient for the patient. Interventions available via the Internet allow patients more autonomy in deciding how to apply these interventions.

Within the field of behavioral medicine, a topic that is receiving increasing attention is “translational behavioral medicine,” i.e., the translation and application of evidence-based, effective interventions from the behavioral medicine domain to patients. The Society of Behavioral Medicine launched a journal devoted to this topic recently. As we have seen in this chapter, scientists working in a behavioral medicine setting do achieve quite acceptable successes in motivating patients with chronic somatic illness to use available, effective, ongoing support systems. This use does impact on major outcomes, for most patients, most of the time. However, patients, healthcare providers, (commercial) companies that pay for and/or reimburse health services, and the society at large do not appear to be wholeheartedly convinced about this effectiveness. It cannot be overstated: incorporating self-management and ongoing self-management support should be part and parcel of regular care for patients with chronic illness (cf., Greenhalgh, 2009). However, while researchers may be confident

that their research-based interventions lead to positive outcomes, it is another matter to convince clinicians to incorporate these findings as regular components of (medical) care (see for instance the paper by Hack et al. (2011), on facilitating the implementation of empirically valid interventions in psychosocial oncology and supportive care). The area of translational behavioral medicine research clearly deserves great attention in future research and clinical applications. Incorporating standards for self-management education into guidelines used by healthcare providers is another more structural way of trying to improve the quality of medical care (cf., Funnel et al., 2011, for diabetes).

The research we have reviewed in this chapter supports the statement that self-management is a crucial part of quality medical care. Whether self-management interventions are suggested, offered, and assessed soon after the contact between patient and healthcare provider, or 3, 6, 12, or 24 months later, is somewhat irrelevant. Patients with the conditions that were discussed in this chapter – asthma, COPD, cancer, cardiovascular disorders, diabetes mellitus, and (rheumatoid) arthritis – will have to self-manage their condition for the rest of their lives. Self-

management and ongoing support for self-management, therefore, should be part and parcel of regular medical care.

Figure 30.4 below (in Fisher et al., *Diabetes Educator* 2007, 33 (Suppl 6), pp. 216S–224S, p. 221S) ties in the Chronic Care Model that we discussed before (p. 8) and the Common Sense Model (p. 886, this chapter) with self-management behaviors. The figure underlines the importance of the connections between the models that are discernable in the figure, and the three levels of variables, indicated in the left-hand side of the figure (cf., Battersby, von Korff, et al., 2010).

The model has implications for medical education as well. We need to educate and teach our physicians-in-training the skills to incorporate self-management techniques in healthcare, enabling them to know how to, for example, support the ongoing self-management of a 76-year old woman with rheumatoid arthritis – and probably more than one comorbid condition. Journals in medical education do pay attention to this issue (e.g., Bowen, Provost, et al., 2010; Holman, 2004). It is important to align medical education with the changes in patterns of morbidity in the next decades.

Disease	Behavioral objectives	Outcomes	Overall objective
Asthma	Symptom perception, symptom control, incorporating asthma in social and psychological life	Reduction of healthcare use, absenteeism from school/work, better QOL	Adapt and self-manage
COPD	Maintain physical activities, maintain social relations	Reductions in depression and anxiety, healthcare use, mortality	Adapt and self-manage
Cancer	Management of cancer treatment and its consequences	Improvement of QOL	Adapt and self-manage
Cardiovascular diseases	Management of physical, psychological, and social consequences of illness and its management	Improved survival, improved QOL	Adapt and self-manage
Diabetes mellitus	Adjust eating behavior, physical activities	Reduction of complications	Adapt and self-manage
Rheumatoid arthritis	Manage consequences of illness in daily life	Reductions in limitations in daily activities	Adapt and self-manage

Schematic representation of behavioral objectives, outcomes, and overall objective in six chronic somatic disorders
QOL quality of life

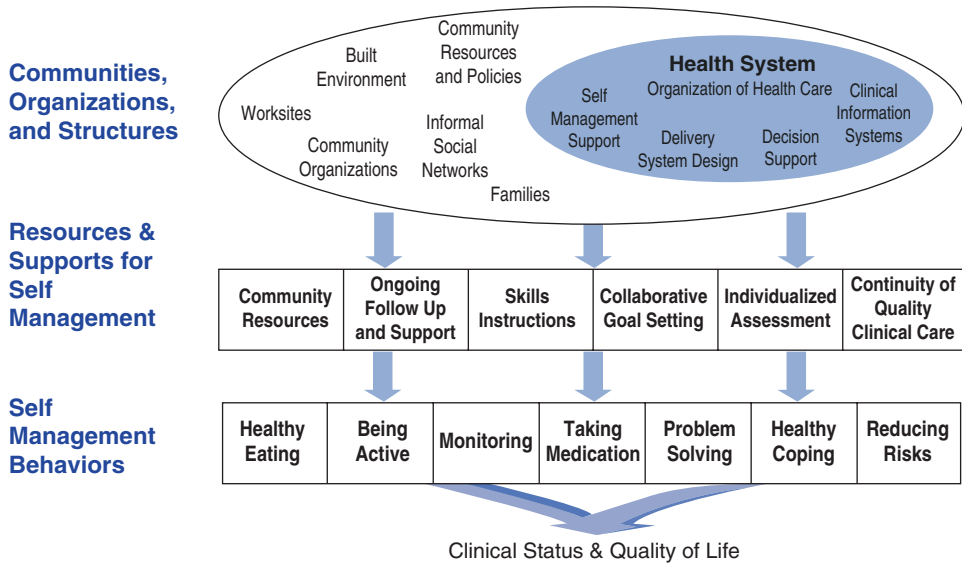


Fig. 30.4 Trilevel model of self-management and chronic care

Wagner, an important contributor to the thinking regarding chronic care management, quite rightly emphasizes the role of academic primary care in this context (Wagner, 2010). In line with our finding about nurses playing a central role in providing ongoing self-management support, Wagner maintains that “increasingly, nurses, medical assistants, or others on a practice team receive training in counseling strategies (e.g., motivational interviewing), and interact regularly with chronically ill patients at visits or by telephone” (p. S637).

Our review of studies on ongoing self-management support is limited – somewhat paradoxically – by the relative success of self-management in people with chronic illness: the number of studies in this area makes it virtually impossible to really adopt a helicopter view of the area. By focusing on review papers, meta-analyses, and Cochrane reviews, we have attempted to deal with this limitation. This research area would be improved with longer follow-up periods, and those providing research funds should also consider the implications of this for grant durations. Patients themselves, and their partners, may beneficially be more fully

involved in the design and delivery of self-management intervention studies.

“The only important indicators of health and wellness are behavioral” – this exciting, albeit somewhat provocative, quote summarizes a major paper by Kaplan: “Behavior as the central outcome in health care” (1990). Given our review of self-management in six chronic somatic disorders, it should be evident that self-management has disease-specific elements, in addition to elements that appear to be valid for all chronic somatic disorders. In the table we present a rough sketch of behavioral objectives of self-management for the six illnesses and the associated behavioral outcomes (cf. Kaplan, 1990). A recent position paper in the *British Medical Journal* examined the concept “health.” Rather than adopting the 1948 WHO definition, the author group took a bold step. They defined health as “the ability to adapt and to self manage” (p. 236, Huber et al., 2011). We think this author group is absolutely right – our chapter hopes to contribute to this viewpoint on health, illness, and quality of life. Therefore, in the table, the ultimate outcome measure is labeled “the ability to adapt and to self-manage.”

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