Disease Management:
The Need for a Focus on Broader
Self-Management Abilities and Quality of Life

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Abstract

The study objective was to investigate long-term effects of disease management programs (DMPs) on (1) health behaviors (smoking, physical exercise); (2) self-management abilities (self-efficacy, investment behavior, initiative taking); and (3) physical and mental quality of life among chronically ill patients. The study also examined whether (changes in) health behaviors and self-management abilities predicted quality of life. Questionnaires were sent to all 5076 patients participating in 18 Dutch DMPs in 2010 (T0; 2676 [53%] respondents). Two years later (T1), questionnaires were sent to 4350 patients still participating in DMPs (1722 [40%] respondents). Structured interviews were held with the 18 DMP project leaders. DMP implementation improved patients' health behavior and physical quality of life, but mental quality of life and self-management abilities declined over time. Changes in patients' investment behavior predicted physical quality of life at T1 ($P < .001$); physical activity, investment behavior (both $P < .05$), and self-efficacy ($P < .01$) at T0, and changes in self-efficacy and investment behavior (both $P < .001$) predicted patients' mental quality of life at T1. The long-term benefits of these DMPs include successful improvement of chronically ill patients' health behaviors and physical quality of life. However, these programs were not able to improve or maintain broader self-management abilities or mental quality of life, highlighting the need to focus on these abilities and overall quality of life. As coproducers of care, patients should be stimulated and enabled to manage their health and quality of life. (*Population Health Management* 2015;18:246–255)

Background

THE COMPLEXITY OF MANY chronic disease profiles demands a patient-centered system of care delivery characterized by long-term coordination among diverse health professionals, such that patients are equipped with the information and skills necessary to act as coproducers of their care and health outcomes are optimized.[1] Too often, however, chronically ill patients are still underdiagnosed and undertreated, and their care rarely incorporates the implementation of primary (ie, to prevent disease onset) and secondary (ie, treatment of patients with known risk factors or in the initial stages of disease) preventive measures.[2] Even in the United States, where interventions to transform primary care practices into Patient-Centered Medical Homes are increasingly common, they show limited improvements in quality of care, suggesting that these interventions need further refinement.[3] The processes and outcomes of chronic care delivery must be changed, and research findings have strongly suggested that such a transformation requires multicomponent interventions, such as disease management programs based on the Chronic Care Model.[1,4,5] Disease management programs involve coordinated interventions for patient populations in which improvement in self-care has been shown to have significant effects.[4–8]

The primary aim of the Chronic Care Model is to redesign and improve the quality of chronic care delivery through a focus on interactions between informed, activated patients and proactive health care teams. It provides a multidimensional framework guiding the replacement of the current system, which is based on acute and reactive care, with planned, population-based care delivery to patients with chronic diseases.[6–8] The model includes 6 interrelated components of the quality of chronic care delivery:

1. Self-management support (ie, empowering patients to manage their own care through planning, goal setting, and problem solving);

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2. Delivery system design (ie, defining health care team members' roles and delivering evidence-based care that patients understand);

3. Decision support (ie, making decisions about care together with patients using evidence-based guidelines and specialists' expertise);

4. Clinical information systems (ie, providing timely reminders for patients and health professionals, planning and coordinating care for individual patients, monitoring health care team performance);

5. Health care organization (ie, promoting effective strategies at all levels to comprehensively change the care system, developing agreements to coordinate care and address quality issues); and

6. Community linkages (ie, developing partnerships with community organizations to support interventions that complement health services, advocating for policy changes that improve patient care).[4–6]

Corresponding primary care practices that employ the Chronic Care Model (1) support the self-management abilities of chronically ill patients through education, lifestyle programs, skills building, and self-efficacy; (2) redesign the way that care is delivered to chronically ill patients; (3) use evidence (eg, care standards, clinical guidelines) to provide quality care; and (4) implement information systems to improve communication and coordination among professionals, provide timely reminders and feedback, increase data visibility at the time of clinical decision making, and monitor the effectiveness of individual care. In primary care practices, these 4 dimensions of chronic care delivery function within the wider context of (5) a health care organization that provides incentives to improve the quality of chronic care delivery, and (6) a community that supports such delivery.

However, the Chronic Care Model is limited by its focus on clinical and functional outcomes and the improvement of health behaviors (eg, smoking cessation, healthy exercise, diet plans)[9–11] while largely neglecting consideration of patients' overall quality of life and well-being.[12] The needs of chronically ill patients necessitate behavioral changes and engagement in activities that promote physical (eg, physical functioning, pain, general health) and mental (eg, vitality, social functioning, mental health) quality of life, which often affect disease control more directly than professional care providers' actions.[13,14] Health care providers should set a patient's quality of life as the primary goal of care, prioritizing it while treating individual illnesses and impairments.[9] Thus, interventions aiming to help patients with chronic conditions develop self-management abilities, enabling them to maintain or improve quality of life (eg, by continued participation in social and other activities), are an important complement to the management of functional decline.[15–18]

Within the context of the Self-Management of Well-being theory, Steverink and colleagues[19] identified abilities of potential importance for the achievement or maintenance of chronically ill patients' well-being, such as self-efficacy (belief in one's ability to accomplish specific goals), initiative taking (self-motivation or an instrumental role in one's physical and mental quality of life), and investment in resources (eg, good health, interests, supportive social relationships) to achieve long-term benefits. Rather than being the process of dealing with losses and suffering from the consequences of living with a chronic disease, these self-management abilities focus on individuals' reserve capacities to realize and sustain quality of life. Indeed, research has revealed that self-management abilities are strongly related to physical health and depressive symptoms among patients with cardiovascular diseases (CVDs), diabetes, or chronic obstructive pulmonary disease (COPD).[15] Furthermore, self-management abilities seem to mediate the relationships between social, cognitive, and physical functioning and well-being among patients with CVD, COPD, and diabetes,[15] and among older adults after hospitalization.[20] However, these studies were all cross-sectional and did not investigate the long-term effects of disease management programs on self-management abilities.

Although it is known that disease management programs based on the Chronic Care Model successfully improve the quality of chronic care delivery[21–23] and prevent disease complications,[24] as indicated by measures of care processes and clinical outcomes,[25] their long-term benefits for health behaviors, self-management abilities, and quality of life have not been established.

Furthermore, the Chronic Care Model incorporates flexibility in the implementation of interventions. Disease management program implementation is known to be a time-consuming and challenging experience. Its demand for complex and multifaceted changes in routine care have led to wide variation in implemented interventions among disease management programs, which is expected to influence patient outcomes.[26] Thus, these programs may incorporate the elements of the Chronic Care Model to various extents using diverse constellations of interventions. To understand the design and effects of disease management programs, this study sought to determine the experiences of such programs and their long-term effects on (1) health behaviors (smoking and physical exercise) and (2) self-management abilities (self-efficacy, investment behavior, initiative taking). As smoking, physical activity, and self-management abilities are expected to affect patients' quality of life, this study additionally aimed to examine whether (changes in) health behaviors and self-management abilities predicted physical and mental quality of life over time. This investigation will improve our understanding of the most important quality of life predictors for chronically ill patients. The findings of this study may have implications for other types of chronic care delivery programs that seek to offer more patient-centered care, thereby improving patients' quality of life.

Methods

A mixed-methods approach was used to describe the experiences of disease management programs. In such an approach, qualitative and quantitative data are gathered simultaneously and combined in the analysis phase to broaden the scope of understanding.

Quantitative analysis

Participants. This study included patients participating in 18/22 disease management programs based on the Chronic Care Model that were implemented in various regions of the Netherlands. Four disease management programs were

excluded because of (1) small sample size (<15 patients); (2) delayed questionnaire distribution, resulting in incomplete data availability; (3) inclusion of hospitalized patients rather than community-based primary care patients; and (4) slightly different questionnaire content to address a specific mental health condition. The 18 disease management programs were characterized as collaborations between care sectors (eg, between general practitioners and hospitals) or within primary care settings (eg, among pharmacists, physiotherapists, dieticians, social workers), and by the population targeted: patients with CVDs (n=9), COPD (n=4), heart failure (n=1), comorbidity (n=1), and diabetes (n=3).[11]

At baseline (T0; 2010), a questionnaire was sent to all 5076 patients participating in the 18 disease management programs. A total of 2676 respondents completed the questionnaire (53% response rate). Two years later (in 2012; T1), a questionnaire was sent to 4350 patients still participating in the disease management programs at that time. A total of 1722 respondents completed the questionnaire (40% response rate). A total of 1209 respondents (representing the 18 disease management programs) completed questionnaires at both measurement points (T0 and T1).

Interventions. Table 1 displays the interventions used within the disease management programs. Self-management is critical to optimal management of chronic diseases. Hence, all disease management programs included such interventions. The most frequently used self-management interventions were lifestyle interventions and personal coaching. Care standards, training and independence of practice assistants, and professional education and training for care providers were used in all of the disease management programs to support professionals in decision making. Implementation of the care standard and working with clinical guidelines was supported by information and communication technologies tools such as integrated information systems. In addition, automatic measurement of process and outcome indicators took place for quality improvements. Many forms of organizational change were applied. Commonly used interventions were delegation of care from specialist to nurse/care practitioner, systematic follow-up of patients, and meetings involving professionals from different disciplines to exchange knowledge/information. Furthermore, most disease management programs cooperate with external community partners. As chronically ill patients often visit their general practitioners as well as specialists (eg, lung specialist, cardiologist), the establishment of protocols and use of treatment and care pathways to refer patients and share information among professionals are important.

Ethical approval. The ethics committee of the Erasmus University Medical Center of Rotterdam approved the study and all participants provided informed consent.

Measures. Physical and mental quality of life were measured using the corresponding components of the Short Form 36 Health Survey (SF-36). Rules for item scoring and scales are available in the SF-36 scoring manual.[27] All scales were transformed to values falling between 0 and 100 to allow comparison among patient groups. Higher scores indicate more positive ratings. According to the scoring rules, selected items and weights derived from the general Dutch population[28] were then used to score physical and mental quality of life. Norm scores to compare mental and physical quality of life to the Dutch population are 50.

Self-management abilities were measured by combining three 3-item subscales assessing (1) the ability to invest in resources for long-term benefits (eg, "Do you keep busy with the things you are good at so that you stay good at them?"), (2) the ability to self-efficaciously manage resources (eg, "Are you able to have friendly contacts with others?"), and (3) the ability to take the initiative (eg, "How often do you take the initiative to get in touch with people who are dear to you?").[29,30] The scale's internal consistency was 0.92. Average self-management ability scores ranged from 1 to 6, with higher scores indicating higher self-management abilities.

Physical activity was assessed by asking respondents how many days per week they were physically active (eg, sport activities, exercise, housecleaning, work in the garden) for at least 30 minutes. Current smoking was assessed with a yes/no question.

The research team assessed background characteristics such as age, sex, marital status, and education. Patients' educational levels were classified using 6 levels ranging from 1 (no school or primary education [≤7 years]) to 6 (university degree [≥18 years]). This item was dichotomized into low (no school or primary education) and high (more than primary education) educational levels.

Statistical analyses. Descriptive statistics were used to characterize the study population. Two-tailed, paired t tests or chi-square tests were used to investigate long-term effects on patients' health behavior, self-management abilities, and physical and mental quality of life over time (difference between T0 and T1). The research team employed a multilevel random-effects model to investigate the predictive role of (changes in) health behavior and self-management abilities on patients' physical and mental quality of life while controlling for patients' quality of life at T0, age, sex, educational level, and marital status. Results were considered statistically significant when 2-sided P values were ≤.05.

Qualitative analysis

For the qualitative part of the study, structured interviews were held with all project leaders from the disease management programs in the Netherlands. A template based on the Chronic Care Model was developed for the collection of qualitative data on various approaches to improve care for chronically ill patients within these programs. Project leaders were asked about the implementation of interventions and their experiences with improving patient outcomes. In addition, they were asked about interventions they tried to implement that were unsuccessful. All interviews were approximately 60–90 minutes in length and were recorded with permission. After finalizing, the template-structured interview data were sent back to the project leaders for member checking and final corrections.

Results

Struggles with self-management

Although the Chronic Care Model is a framework designed to guide the implementation of 6 supportive elements

TABLE 1. OVERVIEW OF INTERVENTIONS IMPLEMENTED WITHIN 18 DISEASE MANAGEMENT PROGRAMS IN THE NETHERLANDS.

CCM Dimension	Intervention	Number of Programs	%
Health care organization	Integrated financing of disease management	9	50
	Specific policies and subsidies for immigrant population	5	28
	Sustainable DMP financing agreements with health insurers	10	56
Community	Communication platform between stakeholders about patients	2	11
	Health market	1	6
	Cooperation with external community partners	15	83
	Multidisciplinary and transmural collaboration	14	78
	Role model in the area	8	44
	Regional collaboration for DMP expansion	8	44
	Treatment and care pathways in outpatient and inpatient care	15	83
	Involvement of patient groups and panels in care design	9	50
	Regional training course	13	72
	Family participation	3	17
Self-Management	Promotion of disease-specific information	14	78
	Individual care plan	13	72
	Lifestyle interventions (eg, physical activity, diet, smoking)	16	89
	Support of self-management (eg, Internet, e-mail, SMS)	2	11
	Telemonitoring	0	0
	Personal coaching	15	83
	Motivational interviewing	16	89
	Informational meetings	6	33
	Diagnosis and treatment of mental health issues	7	39
	Reflection interviews	0	0
	Group sessions for patient and family	5	28
	Cognitive behavioral therapy	1	6
Decision Support	Care standards/clinical guidelines	18	100
	Uniform treatment protocol in outpatient and inpatient care	10	56
	Training and independence of practice assistants	18	100
	Professional education and training for care providers	18	100
	Automatic measurement of process/outcome indicators	16	89
	Use of care protocols for immigrants	1	6
	Audit and feedback	10	56
	Periodic evaluation of interventions and goal achievement	6	33
	Structural participation in knowledge exchange/best practices	11	61
	Quality of life questionnaire	7	39
	Evaluation of health care via focus groups with patients	4	22
	Measurement of patient satisfaction	9	50
Delivery System Design	Delegation of care from specialist to nurse/care practitioner	16	89
	Substitution of inpatient with outpatient care	11	61
	Systematic follow-up of patients	16	89
	One-stop outpatient clinic	3	17
	Specific plan for immigrant population	3	17
	Expansion of chain of care to the secondary care setting	6	33
	Joint consultation hours	3	17
	Meetings of different disciplines to exchange information	17	94
	Monitoring of high-risk patients	13	72
	Board of clients	4	22
	Periodic discussions between care professionals (and patients)	11	61
	Stepped care method	6	33
Clinical Information Systems	Electronic patient records system with patient portal	1	6
	Hospital or practice information system	18	100
	Integrated Chain information system	10	56
	Use of ICT for internal and/or regional benchmarking	14	78
	Creation of a safe environment for data exchange	8	44
	Systematic registration by every caregiver	15	83
	Exchange of information among care disciplines	12	67

CCM, chronic care model; DMP, disease management program; SMS, short message service; ICT, information and communication technologies.

of chronic care delivery, thereby supporting productive interaction between proactive patients and professionals, the project leaders explained that they struggled to implement self-management interventions that really fit the needs of chronically ill patients and stimulated them to become proactive partners in care delivery. Each disease management program successfully implemented a constellation of interventions within each of the 6 dimensions of the Chronic Care Model. Nevertheless, project leaders reported that several attempts to implement self-management interventions were unsuccessful.

The most frequently mentioned interventions that could not be implemented or that were unsuccessful were "reflection interviews," "e-consultation" (eg, via Internet, e-mail, or short message service), "individual care plans," "informational meetings," "involvement of patient groups and patient panels in care design," and "periodic discussion sessions between care professionals and patients." In elaborating on their experiences, project leaders mentioned several reasons for the failure to successfully implement these self-management interventions. Most of the reasons fell into the following categories: (1) lack of patients' interest in using the interventions; (2) patients feeling overwhelmed by the interventions; and (3) patients' preference for personal contact with health care professionals over self-checkups or contact via Internet/e-mail. Finally, project leaders explained that it takes time for interventions to become effective.

Lack of interest.   Project leaders explained that patients' lack of interest in self-management support interventions was a common problem in the implementation of patient-oriented interventions:

We arranged two informational meetings a year for patients to educate them on disease management. Self-management was the subject of our last informational meeting. There was a lack of interest among patients to attend these meetings. We were glad if about 15 people showed up, but often the number of participants was much lower. (Project leader of disease management program 2 [CVD])

The lack of interest among patients negatively influenced professionals' willingness to continue self-management support interventions:

Patients seemed very resistant to joining our reflection interview sessions. So although we wanted to continue with this intervention in our disease management program, we stopped using it. It took too much of our employees' time and effort to stimulate and motivate even only four patients to join. (Project leader of disease management program 16 [COPD])

The same situation was encountered in a CVD management program:

Last year we had a reflection interview of 2 hours duration. This session was led by a representative from a patient organization. Since only 4 patients applied to join this session, we included just 4 health care professionals. It was very difficult to find patients who wanted to join these reflection interviews. Therefore, after the first sessions, we stopped. (Project leader of disease management program 5 [CVD])

Patients feel overwhelmed by interventions.   Lack of interest in some disease management interventions may be caused by the number of interventions offered. Project leaders reported that some patients felt overwhelmed by the self-management interventions:

Especially the physical therapists tried to enhance knowledge of the disease among patients. They, for example, organized a self-management course and had a program to stimulate a healthier lifestyle. This, however, appeared to be problematic in practice. Patients felt that it was all a bit too much. They had to come for their regular checkups, go to the physical therapist to work on a healthier lifestyle, and on top of all that they now also had to join a self-management course and work on enhancing their knowledge of the disease. They just were not up for all of that. (Project leader of disease management program 5 [CVD])

Having to take an active role in their own care process seemed to be too much for patients:

Our experience is that all changes resulting in patients having to show up more often just do not work. Patients do not want to become copilots, they just want to be passengers and show up for their regular checkups four times a year. (Project leader of disease management program 19 [diabetes])

Patients value personal contact.   In interviews, project leaders expressed that patients value personal contact highly. Making patients proactive participants in their care delivery was a particular struggle when it meant that they lost contact with nurses. Patients seemed to prefer personal contact over being self-managers or using e-consultation:

Patients have access to the Chain Information System through the Internet, but they rarely use it. Although health care professionals remind their patients occasionally about this intervention and the ability to log in to the system at home, patients just don't use it. They say, "Oh, we will just ask the doctor." (Project leader of disease management program 2 [CVD])

We wanted to use e-consult for self-management support and personal coaching. A lot of time and effort was put into building this e-consult application for patients to use. Patients could visit Hartjenoord for online coaching from their health care professionals. The idea was to support patients via e-mail using a safe patient portal where they could share information with their health care professionals. This portal, however, has not been used to date by any of the patients. (Project leader of disease management program 3 [CVD])

Some disease management programs focused on training patients to become self-managers instead of aiming to improve interaction and collaboration between patients and health care professionals. For example, one program for patients with diabetes aimed to reduce the protocol requirement of 4 checkups per year by letting patients perform 3 checkups themselves, thereby necessitating only an annual visit to the health care practice. This strategy failed completely:

Patients absolutely do not want this. They don't want to participate in a self-management course and they do not want to do their own checkups. Most of them just want to come for personal consultation. (Project leader of disease management program 19 [diabetes])

This experience led the professionals participating in this program to question the validity of their view on self-management. This concept does not necessarily imply that patients must do everything themselves. The main goals of the Chronic Care Model, as represented by interventions

addressing the 6 dimensions of disease management, ultimately are all aimed at improved interaction between teams of health care professionals and proactive patients. Thus, the maintenance of interaction is important, as participants in this program also learned from their hands-on experience with disease management:

> The most important reason why their self-management interventions failed is that patients want to stay in personal contact with the diabetes nurse. More is happening at these consultation hours than just having your checkup. Patients can ask the diabetes nurse questions about anything related to their disease that they are dealing with and share their concerns. Diabetes nurses have the time available during these checkups for these additional questions and talk about things patients are concerned about. We have a very pleasant and skilled diabetes nurse with whom they feel free to exchange personal information. I think they might want to do the checkups themselves, but don't want to lose the personal contact with the nurse. (Project leader of disease management program 19 [diabetes])

Long-term nature of intervention outcomes.   Much time and effort are required to enhance a single patient's self-management abilities, let alone to see results in a whole group. Results reflecting the effective improvement of self-management abilities by disease management programs may take years:

> Self-management means that patients have to deal with their condition in a proactive manner. But disease management goes even further than that. Motivational interviewing, for example, provides health care professionals with techniques to change thinking and behaviors among patients beyond just empowering and coaching them. It is not just a coaching role of asking patients what they need, how you can help them, and letting them decide what's best. It is even more than that: It's about talking about the dilemmas they are experiencing, what they think is important, and changing their thought and behavior patterns in order to really motivate them to work on changing their lives, which takes much personal time with patients and investment to change. (Project leader of disease management program 10 [CVD])

Findings of quantitative analysis

Table 2 displays the characteristics of patients who completed questionnaires at both T0 and T1. The research team compared baseline characteristics of the 1209 participants who completed both questionnaires to those who completed T0 only. No difference in physical quality of life, physical activity, smoking, educational level, or marital status was found. On average, respondents who completed both questionnaires were older (65.65 ± 9.86 vs. 64.07 ± 10.88 years; $P < .001$) and reported better mental quality of life (49.70 ± 9.79 vs. 48.79 ± 9.89; $P < .05$), self-efficacy (4.43 ± 0.87 vs. 4.35 ± 0.95), investment behavior (4.46 ± 0.91 vs. 4.35 ± 0.95), and initiative taking (4.27 ± 0.95 vs. 4.17 ± 0.98) than those who completed a questionnaire only at T1.

As shown in Table 3, patients' mental quality of life scores decreased significantly over time, whereas their physical quality of life scores improved (both $P < .001$). Mean physical activity scores improved significantly and the percentage of current smokers declined (both $P < .001$). Among self-management abilities, these chronically ill patients showed significant reductions over time in self-efficacy, investment behavior, and ability to take initiative (all $P < .001$).

TABLE 2. CHARACTERISTICS OF PATIENTS PARTICIPATING IN DISEASE MANAGEMENT PROGRAMS AT T0

Characteristic	mean ± standard deviation (range) or percentage	n
Age (years)	65.81 ± 9.90 (20–93)	1189
Sex (female)	45%	1206
Marital status (single)	28%	1207
Low educational level	39%	1190
Mental quality of life (SF-36)	49.70 ± 9.79 (3–73)	1164
Physical quality of life (SF-36)	42.41 ± 10.19 (13–64)	1164
Self-efficacy (SMAS-S)	$4.43 \pm .87$ (2–6)	1193
Investment behavior (SMAS-S)	$4.46 \pm .91$ (1–6)	1195
Taking initiative (SMAS-S)	$4.27 \pm .95$ (1–6)	1195
Physical activity	4.90 ± 2.10 (0–7)	1010
Current smokers	22%	1174

Analyses included only respondents who completed questionnaires at both T0 (2010) and T1 (2012; n = 1209).

SF-36, Short Form 36 Health Survey; SMAS-S, Self-Management Ability Scale–Short version.

The results of multilevel analyses are displayed in Tables 4 and 5. Older age ($P \le .001$) and being single ($P \le .05$) predicted chronically ill patients' physical quality of life over time. After adjusting for patients' physical quality of life at T0, age, educational level, marital status, sex, and changes in investment behavior ($P < .001$) predicted patients' physical quality of life at T1 (Table 4). Female sex ($P < .01$) predicted mental quality of life over time. After adjusting for patients' mental quality of life at T0, age, educational level, marital status, sex, physical activity at T0 ($P < .05$), self-efficacy at T0 ($P < .01$), changes in self-efficacy ($P < .001$), investment behavior at T0 ($P < .05$), and changes in investment behavior ($P < .001$) predicted patients' mental quality of life at T1 (Table 5).

Discussion

This study aimed to determine experiences of various disease management programs and their long-term effects on (1) health behaviors (smoking and physical exercise); (2) self-management abilities (self-efficacy, investment behavior, and initiative taking); and (3) physical and mental quality of life among chronically ill patients. It also examined whether (changes in) health behaviors and self-management abilities predicted physical and mental quality of life over time.

The research team found that disease management program implementation improved patients' health behavior. These findings are in line with those of Hung and colleagues,[31] who found that interventions such as disease management programs based on the Chronic Care Model offer a useful framework for preventive purposes by addressing important risky health behaviors. However, in interviews with project leaders the research team learned that they struggled to help patients become proactive participants in their own care delivery and to enhance their self-management abilities. Self-management abilities decreased over time, despite improvements in health behavior. Similarly, disease management program implementation led to

TABLE 3. LONG-TERM CHANGES IN QUALITY OF LIFE, SELF-MANAGEMENT ABILITIES, AND HEALTH BEHAVIOR

	T0		T1		T1–T0			
	M	SD	M	SD	M	SD	Pa	n
Mental quality of life (SF-36)	49.77	(9.72)	48.63	(9.64)	−1.14	(8.73)	<.001	1117
Physical quality of life (SF-36)	42.42	(10.24)	44.02	(8.88)	1.60	(7.10)	<.001	1117
Self-efficacy (SMAS-S)	4.44	(.87)	4.14	(.86)	−.30	(.78)	<.001	1174
Investment behavior (SMAS-S)	4.47	(.90)	4.36	(.97)	−.11	(.88)	<.001	1177
Taking initiative (SMAS-S)	4.28	(.94)	4.01	(.86)	−.27	(.84)	<.001	1176
Physical activity	4.93	(2.08)	5.61	(1.79)	.68	(2.18)	<.001	900
	%		%				Pb	n
Current smokers	23.7		18.6				<.001	1140

[a]Paired *t* test, T0 vs. T1.
[b]Chi-square test, T0 vs. T1.
  T0, 2010; T1, 2012; M, mean; SD, standard deviation; SF-36, Short Form 36 Health Survey; SMAS-S, Self-Management Ability Scale–Short version.

improved physical quality of life, but a decline in mental quality of life (although only slightly below the average for the Dutch population: 48.63 *vs.* 50.00) over time in chronically ill patients. These findings suggest that the Chronic Care Model and disease management programs based on it focus primarily on clinical and functional outcomes rather than overall quality of life and well-being.[12] To improve self-management abilities and mental quality of life, interventions should thus focus on chronically ill patients' overall quality of life and well-being, rather than solely on the illness or impairment.[9]

  As expected, the research team also found that changes in physical activity and changes in investment behavior predicted physical quality of life at T1. In addition, results showed that physical activity at T0, self-efficacy at T0, changes in self-efficacy, investment behavior at T0, and changes in investment behavior predicted mental quality of life at T1. These results also underscore the importance of

focusing not only on the traditionally addressed behaviors of smoking and physical activity, but also on broader self-management abilities such as investment behavior and self-efficacy.

  Self-efficacy refers to the belief in one's abilities to complete tasks and reach goals, find agreeable activities, have friendly contact with others, and let others know that one cares about them. Investment behavior refers to sufficiently and regularly pursuing interests (eg, hobbies) to keep active, maintaining good contact by devoting time and attention to those who are dear, and keeping busy with the things in which one excels to remain proficient in these activities.[29] Dealing with an illness affects not only functional capacities and clinical outcomes but also broader quality of life aspects, such as anxiety about the impact of an illness on oneself and one's family, and fear about the financial impact of an illness.[32,33] Paying attention to the worries and concerns of chronically ill patients and

TABLE 4. PREDICTORS OF PHYSICAL QUALITY OF LIFE AT T1, AS ASSESSED BY MULTILEVEL REGRESSION ANALYSES
(RANDOM INTERCEPTS MODEL, N = 810)

	β	SE	B	SE
Constant	43.55***	.22	22.74***	2.27
Physical quality of life (SF-36) (T0)	6.43***	.23	.62***	.02
Age (T0)	−.96***	.24	−.09***	.02
Marital status (single) (T0)	−.61*	.23	−1.34*	.50
Low educational level (T0)	−.02	.22	−.07	.46
Sex (female) (T0)	−.01	.22	−.02	.45
Physical activity (T0)	.28	.30	.13	.14
Change in physical activity (T1–T0)	.37	.28	.17	.13
Percentage of current smokers (T0)	−.43	.24	−1.01	.57
Change in percentage of current smokers (T1–T0)	−.10	.24	−.32	.81
Self-efficacy (SMAS-S) (T0)	−.31	.41	−.33	.45
Change in self-efficacy (SMAS-S) (T1–T0)	−.42	.29	−.54	.38
Investment behavior (SMAS-S) (T0)	.76	.41	.81	.45
Change in investment behavior (SMAS-S) (T1–T0)	1.11***	.32	1.28***	.37
Taking initiative (SMAS-S) (T0)	−.30	.46	−.31	.48
Change in taking initiative (SMAS-S) (T1–T0)	−.10	.35	−.12	.42

  ***P ≤ .001, **P ≤ .01, *P ≤ .05 (2-tailed).
  Multilevel analyses included only respondents who filled in questionnaires at both T0 and T1. Listwise deletion of missing cases resulted in the inclusion of 810 cases in multilevel regression analyses.
  SE, standard error; SF-36, Short Form 36 Health Survey; T0, 2010; T1, 2012; SMAS-S, Self-Management Ability Scale–Short version

TABLE 5. PREDICTORS OF MENTAL QUALITY OF LIFE AT T1, AS ASSESSED BY MULTILEVEL REGRESSION ANALYSES
(RANDOM INTERCEPTS MODEL, N = 810)

	β	SE	B	SE
Constant	48.07***	.26	9.74***	2.67
Mental quality of life (SF-36) (T0)	5.18***	.31	.52***	.03
Age (T0)	.19	.30	.02	.03
Marital status (single) (T0)	.25	.29	.55	.63
Low educational level (T0)	−.21	.28	−.42	.56
Sex (female) (T0)	−.73**	.28	−1.45**	.55
Physical activity (T0)	.91*	.37	.42*	.17
Change in physical activity (T1–T0)	.42	.35	.19	.16
Percentage of current smokers (T0)	−.16	.31	−.37	.70
Change in percentage of current smokers (T1–T0)	.09	.30	.29	1.00
Self-efficacy (SMAS-S) (T0)	1.49**	.52	1.65**	.58
Change in self-efficacy (SMAS-S) (T1–T0)	1.69***	.37	2.15***	.47
Investment behavior (SMAS-S) (T0)	1.22*	.52	1.30*	.56
Change in investment behavior (SMAS-S) (T1–T0)	1.91***	.41	2.19***	.47
Taking initiative (SMAS-S) (T0)	−.38	.58	−.39	.60
Change in taking initiative (SMAS-S) (T1–T0)	.57	.43	.68	.52

***$P \leq 0.001$, **$P \leq 0.01$, *$P \leq 0.05$ (2-tailed).

Multilevel analyses included only respondents who filled in questionnaires at both T0 and T1. Listwise deletion of missing cases resulted in the inclusion of 810 cases in multilevel regression analyses.

SE, standard error; SF-36, Short Form 36 Health Survey; T0, 2010; T1, 2012; SMAS-S, Self-Management Ability Scale–Short version.

investing in their abilities to cope with them is important. The finding that patients do not want to lose personal contact with health care professionals supports this notion. Such contact provides the opportunity to talk about all the concerns related to dealing with a chronic disease, which is valued highly by patients and is not interchangeable with e-consultation, patient portals for the online exchange of information, or other interventions perceived by patients to require them to ''do everything themselves.'' These contacts were not sufficient to stop the decline of self-management abilities and mental quality of life as consequences of living with a chronic condition.

Although the disease management programs successfully improved the quality of chronic care delivery,[21–23] this study shows that the programs struggled with self-management support in the sense of making chronically ill patients proactive in their care and letting them self-manage their condition. The findings of this study are not typical for the Netherlands alone. A qualitative study conducted by Elissen and colleagues[34] showed that self-management support for patients with chronic diseases is far from adequate in most European countries, and that approaches to such support appear to be the least implemented and most challenging among the elements of the Chronic Care Model.[35]

These findings emphasize the need for a better understanding of how we can encourage patients and health care professionals to engage in productive interactions, thereby improving mental and physical quality of life outcomes. The implementation of interventions aimed at strengthening chronically ill patients' investment behavior and self-efficacy is expected to be beneficial, but it requires a different view of care delivery. Such delivery should be responsive to the needs, values, and expressed preferences of individual patients, and should move beyond being just an object of disease.[36] Thus, health care professionals must have an understanding of the patient's context.[37] Berwick[38] suggested that effective care delivery implies that health

care professionals are ''guests'' in patients' lives, rather than patients' ''hosts'' in the health care system. Such care has proven to lead to better patient outcomes.[39] Effective interaction requires the acquisition and use of knowledge of the patient as a whole, unique person,[40] which in turn requires communication skills and psychological counseling techniques that traditionally have not been part of most medical professionals' training.[41,42]

This study has several limitations. First and most importantly, it did not include control groups corresponding to the patient groups, preventing examination of whether the observed changes over time differed from those in chronically ill patients not enrolled in disease management programs. Second, differences were found between respondents who completed questionnaires only at T0 and those who also completed follow-up questionnaires (T0 and T1). Respondents who completed questionnaires at both time points were, on average, older and reported better mental quality of life and self-management abilities than those who provided responses only at T0, pointing to nonresponse bias. Therefore, the research team performed additional analyses and divided the population at T0 into 2 groups (higher and lower mental quality of life, using the median mental quality of life score as a cutoff point) to investigate whether predictors of quality of life in both groups were the same. The results were very similar. Broader self-management abilities are important quality of life predictors in patients with low as well as high mental quality of life, suggesting that the associations found over time are robust despite nonresponse bias.

Some of the findings may be related to the Dutch welfare system. During the past decades the Dutch government played a key role in the protection and promotion of the economic and social well-being of citizens. This may have influenced attitudes of chronically ill patients to participate in certain interventions. The welfare state is further developed in western European countries compared to the United

States. Participation levels among chronically ill patients may vary between countries depending on their welfare system. However, this situation is changing in Europe; many western countries shift increasing societal burdens from the government to communities.[43] Finally, no incentives were provided to patients to participate in the interventions offered by the disease management programs. Incentives to participate may increase their involvement in certain interventions. Incentives that have been identified as useful to enhance patient participation range from small incentives (eg, gift cards, presents), to employers or health insurers offering reductions in health insurance premiums to people participating in self-management interventions.[44]

Conclusion

The long-term benefits of disease management programs based on the Chronic Care Model in the Netherlands include the successful improvement of chronically ill patients' health behaviors and physical quality of life. However, these programs did not successfully improve or even maintain broader self-management abilities or mental quality of life, which declined over time.

These findings highlight the need to focus on broader self-management abilities (self-efficacy, resource investment, initiative taking) and overall quality of life rather than physical functioning, disease limitations, and lifestyle behaviors alone, and to protect time for personal contact between patients and health care professionals to discuss concerns about dealing with chronic illness. Such contact is not interchangeable with e-consultation or the online exchange of information via a patient portal; it is a requirement for truly effective and productive interaction between chronically ill patients and teams of health care providers.

The implementation of interventions that meet the needs of patients while enhancing their self-management abilities and making them proactive participants in their care delivery poses a challenge. Individuals' ability to take care of themselves as best and as long as possible is becoming increasingly important. Better self-management abilities can prevent worsening of a disease, allowing patients to maintain physical as well as mental quality of life and thereby relieving the pressure on the health care system caused by the increasing demand for care and support. Spending more time with chronically ill patients and attending to their broader needs may help them remain independent and healthy for a longer period of time and prevent use of more expensive health care. This research clearly showed that disease management programs struggle to effectively reach chronically ill patients and train them to be effective coproducers (eg, informed, activated participants) in care delivery. As coproducers of chronic care, chronically ill people should be stimulated and made capable of managing their own health and quality of life. To obtain the best possible health gains with scarce public resources, preventive measures that enhance chronically ill patients' commitment to their own health and support lifestyle improvements are increasingly needed.

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