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Jaap Trappenburg, Tiny Jaarsma, Harmieke van Os-Medendorp, Helianthe Kort, Niek de Wit,
Arno Hoes and Marieke Schuurmans

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Self-management: *one size does not fit all*

Letter to the editor

Jaap Trappenburg, PhD, PT

University Medical Center Utrecht
Department of Rehabilitation, Nursing Science & Sports
Heidelberglaan 100
PO 85500
3508 GA Utrecht
The Netherlands
j.c.a.trappenburg@umcutrecht.nl

Nini Jonkman, MSc

University Medical Center Utrecht
Department of Rehabilitation, Nursing Science & Sports
Heidelberglaan 100
PO 85500
3508 GA Utrecht
The Netherlands
N.Jonkman@umcutrecht.nl

Tiny Jaarsma, PhD, MD

University of Linköping
Department of Social and Welfare studies
Division of Health, Activity and Care
581 83 LINKÖPING
Sweden
tiny.jaarsma@liu.se

Harmieke van Os-Medendorp, PhD, RN

University Medical Center Utrecht
Department of Dermatology
Heidelberglaan 100
PO 85500
3508 GA Utrecht
The Netherlands

Helianthe Kort, PhD

Eindhoven University of Technology /
University of Applied Sciences Utrecht
Den Dolech 2
PO 513
5600 MB Eindhoven

Niek de Wit, PhD, MD

University Medical Center Utrecht
Julius Center for Health Sciences and Primary Care
Heidelberglaan 100
PO 85500

3508 GA Utrecht
The Netherlands

Arno Hoes PhD, MD

University Medical Center Utrecht
Julius Center for Health Sciences and Primary Care
Heidelberglaan 100
PO 85500
3508 GA Utrecht
The Netherlands

Marieke Schuurmans, PhD, RN

University Medical Center Utrecht
Department of Rehabilitation, Nursing Science & Sports
Heidelberglaan 100
PO 85500
3508 GA Utrecht
The Netherlands
M.J.Schuurmans@umcutrecht.nl

Self-management and the chronic disease epidemic

Chronic diseases are the leading causes of mortality, accounting for 60% of all deaths worldwide¹. Driven by an aging population, demographic trends, future life-style patterns and changes in diagnostics, future projections indicate that the burden of chronic disease will substantially increase over the next decennia^{2,3}. The number of patients suffering from multiple chronic conditions will show a proportionally large increase. The burden of meeting the needs of this growing number of people will fall upon already over-stretched health care services that are struggling to cope with the demands of acute care let alone the needs of those with long-term health condition⁴. As a result, there has been a shift away from paternalistic models of health care that sited the patient in the role of passive recipient towards more active involvement of patients in dealing with the day-to-day realities of chronic disease⁵. A promising approach to improving outcomes and reducing health care costs associated with chronic conditions is “self-management,” whereby individuals, in collaboration with health-care professionals, assume greater responsibility for health care decisions⁵. Self-management is one of the four major components of the Chronic Care Model and involves both the community and the health-care system⁶. It presupposes that when “Informed Activated Clients” interact with a “Prepared, Proactive, Practice Team,” the results are improved functional and clinical outcomes⁴.

It is important to understand the difference between self-management support and patient education, given that these terms are often mistakenly used synonymously. The goals of self-management support are different from of patient education. Patient education refers to traditional, largely didactic, instruction provided to patients which focuses mainly on transfer of knowledge. Self-management support is defined as the systematic provision of supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support⁷. Although self-management interventions often also contain didactic strategies, the pivotal objective is to change behavior, which is essential to boot a sequence of effects⁸. Improved self-management behavior is expected to lead to better disease control which should, in turn, lead to better patient outcomes, reduced use of health care services and ultimately to reduced costs and increased patient satisfaction. Core self-management behavioral skills are problem solving, decision making, effective resource utilization, forming of a patient/health care provider partnership, and taking action⁹.

Self-management: is it effective?

Over the past decade self-management programs have been developed with good progress and a gradually increasing body of evidence. Table 1 illustrates the pooled evidence from meta-analyses emerging, which indicates that self-management in patients with, asthma¹⁰, chronic heart failure¹¹,

COPD¹², diabetes type-2 (DM-II)¹³, hypertension¹⁴, musculoskeletal pain¹⁵ and patients on oral anticoagulation¹⁶ improves a variety of outcomes such as improved disease-specific outcomes, quality of life, self-management behavior, and reduced healthcare costs. Given these encouraging results one might conclude that nothing should prevent policy makers and healthcare professionals from robust implementation of self-management in routine care. Although improving patients' self-management skills apparently seems meaningful and harmless, in 2012 alone three large trials reported negative¹⁷ or even adverse outcomes including unexplained higher mortality rates^{18;19} (one mainly focusing at telemonitoring). This might indicate that self-management interventions are not necessarily harmless. Should this temper our enthusiasm for self-management support? Forest plots in meta-analyses seem to favor self-management, yet it is important to realize that available trials are characterized by large heterogeneity in self-management approaches in terms of mode, dose, intensity, delivery, etc., resulting in large variance in effect sizes. This substantially hampers our understanding of the effectiveness of self-management.

Self-management: what works best?

Several meta-analysis have attempted to evaluate possible shifts in effect size for different program characteristics but were largely unrevealing^{11;13;14;20}. However, in patients with COPD⁹ and asthma¹¹ the addition of action plans for self-treatment of exacerbations is associated with a somewhat larger reduction in healthcare utilization. In DM-II, improvements in glycaemic control seem more pronounced when psychosocial behavioral techniques are used^{20;21}. The addition of self-adjusted therapy in patients on oral coagulation seems dominant compared to self-monitoring alone in terms of a slightly greater reduction in thromboembolic events and mortality¹⁶. Generally, it can be concluded that aggregated / subgroup analyses from the literature do not yet sufficiently answer what type of self-management support is most effective. In itself, that is not surprising, since included trials did not only evaluate highly heterogeneous interventions, but also targeted heterogeneous patient populations using varied outcome measures. Presently, evidence is lacking on what is the contribution of each component in explaining variance in effect size. Without this knowledge, compiling an optimal program package in terms of e.g. mode, dose, intensity and delivery is hindered, as are effective implementation strategies.

One size does not fit all: urge for tailored interventions

A self-management program is not equal to prescribing patients a drug but instead a classic example of a 'complex intervention' – a treatment strategy containing several interacting components and varying dimensions of complexity (i.e. variability in delivery, organizational levels, outcomes, etc.)²². When applied to subtly different target populations or healthcare settings these interventions can

produce substantially variable results. Although we can conclude that self-management is effective in mean group-outcomes, individual trials report that a substantial proportion of patients do not comply or do not respond to these interventions. The large variance in effect size between patients presumes that 'one size does not fit all'. So far, little is known on factors distinguishing compliers and responders from non-compliers and non-responders. It is still unknown whether in this group a subtle change in the components, mode or intensity of a self-management intervention would have been sufficient to optimize outcomes. It is likely that for a selection of patients some self-management assistance is already sufficient in adequately controlling their disease, while other patients only benefit from more intense self-management support, case-management or even passive surveillance (monitoring). Furthermore, it is plausible that a selection of patients particularly benefit from face-to-face contacts, while sophisticated E-health solutions are suitable for other patients. Given the fact that not all patients seem to benefit from current 'one size fits all' interventions, effect size might substantially be increased by tailoring programs to the individual. Increased knowledge on the program- and patient-related facilitators and barriers of success of self-management interventions can facilitate the development of tailored interventions based on individual patient profiles and preferences.

Conclusion and future directions

Self-management for people with chronic diseases is now widely recognized as an essential part of treatment. Despite the high expectations and the growing body of evidence in terms of effectiveness, a wide application of self-management programs is inhibited due to several challenges. Meta-analytic findings indicate self-management to have added value in only a selection of outcome measures and they report large variance in effect size both between studies and target populations. Worldwide, a variety of complex and multifactorial interventions have been evaluated in very heterogeneous patient populations keeping healthcare professionals guessing on what works best and what works in whom. There is a lack of empirical evidence about the essential features of self-management programs and to what extent and in which direction effect size changes over different target populations. More research is needed to try and establish the optimum design of dynamic self-management programs, whereby content, mode and intensity are tailored based on the particular chronic disease and characteristics of the patient.

In 2011, after receiving a grant from The Netherlands Organization for Health Research and Development (ZonMw) a unique international research collaboration was launched under the acronym Tailored Self-management & E-health (TASTE). The TASTE research line aims at systematically filling the knowledge gap needed for the development of tailored interventions, including e-health applications, based on individual patient profiles and preferences. More specific

aims of this research program are to: 1. further identify (non)compliers and (non)responders, identify determinants of self-management capacity/skills and determinants of change following self-management support, 2. increase the understanding in the dose-response relationship of self-management interventions, 3. increase the understanding in the essential clinical competences of healthcare providers providing tailored self-management support, 4. develop a generic intervention which allows tailoring mode, dose and content of self-management education, case-management and monitoring according to pre-specified patient profiles and preferences 5. develop disease-specific modules that can be added to generic self-management interventions, 6. evaluate (cost-)effectiveness of a generic tailored self-management intervention.

The scientific objectives are carried out in a systematic and carefully phased approach using the model for development of complex interventions²². This model serves as a framework to which hierarchical studies of different nature and methodology can be attached. Within TASTE, a lot of attention will be paid to making the most out of what is already known. Innovative techniques such as meta-regression and Individual Patient-Data (IPD) meta-analysis²³ will be used to systematically unravel success of self-management in terms of patient- and program characteristics.

Consolidation of this research line is strengthened by close collaboration with other universities (both Dutch and abroad), primary care organizations, patient organizations, educational institutes and professional organizations. Involvement of experienced self-management researchers from University Twente (The Netherlands), Leiden University Medical Center (The Netherlands), Linköping University (Sweden), Stanford University (California, US), McGill University (Canada), Pace University (US), University of Warwick (UK), Taipei University (Taiwan) and University of Leuven (Belgium) substantially contribute to the health behavioral and methodological expertise of the research team. Within this collaboration, TASTE aims at substantially increasing the understanding of the interaction of patient- and program characteristics in defining the success of self-management interventions, which may facilitate the development of future interventions.

Table 1. Evidence for effectiveness of self-management based on meta-analysis in several chronic conditions.

Chronic disease	Meta-analysis	Comparison	# Included RCT's / patients	Key significant findings					
				Disease specific outcomes		Patient Reported Outcomes		Healthcare utilization	
				parameter	pooled result	parameter	pooled result	parameter	pooled result
Arthritis / Chronic musculo-skeletal pain	Du et al. 2011	Self-management education vs. usual care	19/ ?	Arthritis-related pain 4 months 6 months 12 months	SMD: -0.23 [-0.36,-0.10] SMD: -0.29 [-0.41,-0.17] SMD: -0.14 [-0.23,-0.04]	Arthritis-related disability 12 months	SMD: -0.17 [-0.27,-0.07]		
Asthma	Gibson et al. 2003	Self-management education +/- regular review vs usual care	36/4593	Nocturnal asthma Peak Flow (l/min)	RR: 0.67 [0.56,0.79] WMD: 0.18 [0.07,0.29]	HRQoL miscellaneous	WMD: 0.29 [0.11,0.47]	Hospitalization ER visits Days off work	RR: 0.64 [0.50-0.82] RR: 0.82 [0.73,0.94] WMD: -0.18 [-0.28,-0.09]
CHF	Jovicic et al. 2006	Self-management education vs. usual care	6/857					1-year readmission - all cause - CHF-related	OR: 0.59 [0.44,0.88] OR: 0.44 [0.27,0.71]
COPD	Effing et al. 2007	Self-management education vs. usual care	15/2239	Dyspnea Borg scale	WMD: -0.53 [-0.96,-0.10]	HRQoL SGRQ total	SMD: -2.58 [-5.14,-0.02]	≥ 1 respiratory-related hospital admission/year	OR: 0.64 [0.47,0.89]
DMII	Deakin et al. 2009	Group based self-management vs. usual care	11/1532	HbA1c (%) 4-6 months 12-14 months 2 years FB glucose (mmol/L) 12-14 months Weight (kg) 12-14 months SBP (mmHg) 4-6 months	WMD: -1.35 [-1.93,-0.78] WMD: -0.82 [-0.99,-0.65] WMD: -0.97 [-1.40,-0.54] WMD: -1.17 [-1.63,-0.72] WMD: -1.61 [-2.97,-0.25] WMD: -5.37 [-9.53,-1.21]	Diabetes knowledge	WMD: 1.0 [0.7, 1.2]	Diabetes medication	OR: 11.8 [5.2,26.9]
DMII – not using insuline	Malanda et al. 2012	Self-monitoring of blood glucose vs. usual care	12/3259	HbA1c (%) 6 months	WMD: -0.26 [-0.39,-0.13]				
Hypertension	Chodosh et al 2005	Self-management education vs usual care	13/ ?	SBP (mmHg) DBP (mmHg)	PES: -0.39 [-0.51,-0.28] PES: -0.51 [-0.73,-0.30]				
Patients on long-term oral anticoagulation	Garcia-Alamino et al. 2012	Self-monitoring +/- self-management education vs regular care	18/4723	Thromboembolic events All-cause mortality	RR: 0.50 [0.36,0.69] RR: 0.64 [0.46,0.89]				

SMD = Standardized Mean Difference; CHF = Chronic Heart Failure; COPD = Chronic Obstructive Pulmonary Disease; WMD = Weighted Mean Difference; HRQoL = Health-Related Quality of Life; SGRQ= SGRQ: Saint George Respiratory Disease Questionnaire (lower scores represent better quality of life); DMII = diabetes mellitus type 2; HbA1c = Glycated haemoglobin; FB = Fasting Blood; RR = Risk Ratio; ER = Emergency Room; DBP = Diastolic Blood Pressure; PES = Pooled Effect Size

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