How to Become an Agent of One's Own Healing Processes: Self-Management for Chronically Ill Patients in Integrative Health Care

Bettina Berger^{a,b} Peter Heusser^{b,c}

^a Chair for Theory of Medicine, Integrative and Anthroposophic Medicine, Witten/Herdecke University, Herdecke, Germany;

^b Institute of Integrative Medicine, Witten/Herdecke University, Herdecke, Germany;

^c Senior Professorship for Medical Anthropology, Witten/Herdecke University, Herdecke, Germany

Engage Patients!

‘Knowing that the most important strategy for fostering health is to engage patients in better lifestyle choices, we seek to develop our skills to activate patients to be self-responsible, to strengthen their resilience, and become captains of their own healing processes’ – this passage was part of the Berlin Agreement of April 2017 authored by the Presidents of the World Congress on Integrative Medicine and Health 2017 in Berlin, Brinkhaus et al. [1], and the other members of the International Organizing Committee.

This was one of the first times that fostering of patient competencies was emphasized explicitly within the discourse of integrative health care. Usually, integrative medicine and health focus on medical concepts, professional competencies, and patient-therapist interaction, but the Berlin Agreement formulated the need to enable patients to take over the responsibility for their own health. This statement can be seen in the context of the important paradigm change from understanding a patient as somebody who must be *treated* to somebody who can *develop* own skills to mobilize health-related resources. But how can we support people with chronic diseases in developing these skills, to become ‘agents’ instead of staying ‘patients’?

When I – coping with a type-1 diabetes mellitus since 40 years – happened to suffer from depression, standard interventions did not help me. My depression was increased by the prognosis of potential fatal pathogenic developments. Nor could I arrange myself with the empathic but helpless reaction of complementary medicine doctors.

What was helpful for me was to behave and to be treated as an agent of my own condition. From my viewpoint, this included relevant diagnostic data and medical support in looking for an appropriate treatment option and making my decision to choose unconventional therapeutic interventions, biographic introspection, and finding a new meaning by using spiritual resources. Based on these experiences and knowing the research on patients’ needs in relation to self-management (SM) [2, 3], the question arose to what extent patients can expect health care professionals to provide support, information, and skills development, which are needed to transform patients’ attitudes towards their health care and for them to gain control over their lives. After all, patients with chronic diseases have

to make many health-related decisions – sometimes daily, and they look for support to transform and manage their situation.

SM may therefore be understood as an ability that necessarily has to be developed; however, for patients seeking integrative health care interventions, the term ‘self-management’ should not only be related to the disease but to the whole person, including his/her biographic, emotional, social, mental, and spiritual dimensions, and being embedded into a salutogenetic approach [4]. Thus, healing will be understood as the ability to use internal and external resources to develop self-leadership. It goes, however, without saying that the intention to equip patients with SM skills should not be misinterpreted as the opportunity to leave patients alone when they ask for support.

Current Relevance of Self-Management in Health Care

In health care systems, SM programs for patients with chronic conditions have become relevant fields of research, with ‘expert patient’ programs being implemented [5–7]. Already in 1997, the chronic care model was introduced by Wagner [8, 9]. It includes the following aspects: professional partnership, involving collaborative care and SM training. SM training complements traditional patient education supporting patients to acquire the best possible quality of life with their chronic condition. Whereas traditional patient education offers information and technical skills, SM training teaches problem-solving skills. A central aspect in SM is self-efficacy – the confidence to have the right resources available to solve a problem or a difficult situation and to reach the desired goal. Self-efficacy is enhanced when patients succeed in solving self-identified problems. Teaching SM skills is more effective than just imparting information. SM education programs for patient groups with a variety of chronic conditions may improve outcomes, reduce costs, and should become an integral part of high-quality primary care [6, 10].

Supporting patients’ SM requires special competencies on the side of the health carers and the medical system. People living with a chronic disease intend to stay as independent as possible in their daily life, and health care professionals should help them to do so [11]. Yet, the implementation of SM in daily praxis is still limited. Barriers for the implementation are mainly related to a lack of health literacy among patients, a lack of health care professionals’ belief in their patients’ abilities, as well as a lack of training during medical education [2, 11]. Therefore, basic, interactive, and critical health literacy is regarded as one important endpoint to improve patients’ SM abilities [12].

Self-Management in Integrative Medicine and Health

Until now, the improvement of self-care or SM abilities has not been defined as a strategic aim of integrative health care. For exam-

ple, within the National Center for Complementary and Integrative Health, belonging to the National Institutes of Health in the USA, the self-care or SM abilities of patients with chronic diseases are not seen as important strategic aims of integrative health care, only for pain-management is active self-care recognized as important [13]. Integrative health care is regarded as the basis for patient-centered care [14]. How can the importance of patients’ ability to cope with their conditions be overlooked? When focussing mainly on empathic, communicative patient-doctor interaction, a hidden paternalism might prevail behind the concept of patient-centered care.

However, one main reason why patients seek integrative medicine is their wish to do something for themselves and to ask for options of self-activation. Of course, the development of patient competencies and SM skills is not a matter of a short doctor-patient encounter; instead, a longer training program with iterative learning cycles and implementation in the daily lives of affected persons is required.

Some studies stated that users of complementary and alternative medicine have a higher internal locus of control, but others could not confirm these results [15, 16]. This discrepancy may lead to the interpretation that patients seeking complementary or integrative medical approaches are not always ready and willing to take over an active role, and some may nevertheless feel treated quite well with rather paternalistic concepts.

These considerations show that the topic of SM skills of patients is an important and timely issue, especially in the context of the patient-oriented approaches of integrative health care, but that – paradoxically – it has not yet gotten the attention it deserves. For this reason, we dedicate this special issue of COMPLEMENTARY MEDICINE RESEARCH to the topic of SM, offering 6 new contributions to the discussion:

1) Dieter Melchart and his group in Munich developed a complex individual health management program, inviting people to work on their own health, supported by an individual feedback system. Melchart’s [17] self-managed lifestyle interventions coach people individually to prevent diseases. In this study, his group analyzed patients who dropped out from the intervention in order to find out which persons do not benefit from the approach of daily feedback [18].

2) Michaelis et al. [19] present an unusual case report format – based on qualitative data and contrasting 2 cases. They use patients’ ability to introspect biographically to discover behavioral patterns together with them. Based on this assisted introspection, participants are enabled to change their patterns and partly even to change their physical symptoms and improve seizure control. This concept had been developed by a woman with epilepsy on her own [20] and shows the ability of affected persons to use their condition as a teacher. This paper shows that the development of ‘inner wisdom’ is a demanding process of self-awareness, which is rendered possible by the assistance of somebody.

3) Patients seeking complementary health care approaches are said to be willing to do something for themselves. Therefore, we included the study of Lynning et al. [21] from the Danish Multiple

Sclerosis Society who asked their members about self-help strategies. The article shows how many patients use SM strategies. This invites discussion as to how far a differentiation between complementary and conventional approaches is relevant with respect to the question of patients' self-activity.

4) Büssing et al. [22] developed and offer an instrument to assess the readiness of patients to take responsibility for their own health. This is of particular interest with regard to persons attending health prevention and intervention programs of mind-body medicine, which encourage and support them in changing their attitudes and health behaviors.

5) The article of Berger et al. [23] describes a complementary intervention as a first part of the evaluation of a complex integrative intervention, which appears to work well in practice, but is not

appropriately evaluated yet. This concerns the salutogenetic aspects of a training program for children with type-1 diabetes mellitus, which is based on conventional training, but comprehensively extended according to the principles of anthroposophic medicine. A learning cycle between therapists and patients is described as the central element in this curriculum to support SM.

6) Baars et al. [24] demonstrate the specific contributions of anthroposophic health care to the promotion of SM of patients, using results from a patient inquiry related to self-activation.

Of course, these articles can contribute only a few elements to the discourse about SM in integrative health care. But they show how important it is. In the future, we do need a more systematic approach to this issue.

References

- Brinkhaus BG, Haramati HU, Falkenberg TS, et al: The Berlin Agreement: Self-Responsibility and Social Action in Practicing and Fostering Integrative Medicine and Health Globally. Version April 16, 2017. www.ecim-icmr.org/fileadmin/ecim-icmr/editors/documents/Berlin_Agreement_on_Self-Responsibility_160417.pdf, 2017.
- Roberts NJ, Younis I, Kidd L, Partridge MR: Barriers to the implementation of self management support in long term lung conditions. *London J Prim Care (Abingdon)* 2012;5:35–47.
- Wortz K, Cade A, Menard JR, et al: A qualitative study of patients' goals and expectations for self-management of COPD. *Prim Care Respir J* 2012;21:384–391.
- Franzel B, Schwiengershausen M, Heusser P, Berger B: Individualised medicine from the perspectives of patients using complementary therapies: a meta-ethnography approach. *BMC Complement Altern Med* 2013; 13:124.
- Foster G, Taylor SJ, Eldridge SE, et al: Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database Syst Rev* 2007; (4):Cd005108.
- Kuo CC, Lin CC, Tsai FM: Effectiveness of empowerment-based self-management interventions on patients with chronic metabolic diseases: a systematic review and meta-analysis. *Worldviews Evid Based Nurs* 2014; 11:301–315.
- Richardson J, Loyola-Sanchez A, Sinclair S, et al: Self-management interventions for chronic disease: a systematic scoping review. *Clin Rehabil* 2014;28:1067–1077.
- Wagner EH, Bennett SM, Austin BT, et al: Finding common ground: patient-centeredness and evidence-based chronic illness care. *J Altern Complement Med* 2005;11(Suppl 1):S7–15.
- Von Korff M, Gruman J, Schaefer J, et al: Collaborative management of chronic illness. *Ann Intern Med* 1997; 127:1097–1102.
- Bodenheimer T, Lorig K, Holman H, Grumbach K: Patient self-management of chronic disease in primary care. *JAMA* 2002;288:2469–2475.
- Anderson RM, Funnell MM: Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. *Patient Educ Couns* 2005;57:153–157.
- Berger B, Gerlach A, Groth S, et al: Competence training in evidence-based medicine for patients, patient counsellors, consumer representatives and health care professionals in Austria: a feasibility study. *Z Evid Fortbild Qual Gesundhwes* 2013;107:44–52.
- National Center for Complementary and Integrative Health: 2016 Strategic Plan: Exploring the Science of Complementary and Integrative Health. National Institutes of Health, 2016, https://nccih.nih.gov/sites/nccam.nih.gov/files/NCCIH_2016_Strategic_Plan.pdf.
- George M: Integrative medicine is integral to providing patient-centered care. *Ann Allergy Asthma Immunol* 2015;114:261–264.
- Ebel MD, Rudolph I, Keinki C, et al: Perception of cancer patients of their disease, self-efficacy and locus of control and usage of complementary and alternative medicine. *J Cancer Res Clin Oncol* 2015;141:1449–1455.
- Baum J, Langer CJ, Evans T, et al: Does perceived control predict Complementary and Alternative Medicine (CAM) use among patients with lung cancer? A cross-sectional survey. *Support Care Cancer* 2014;22:2465–2472.
- Melchart D, Doerfler W, Eustachi A, et al: The talent study: a multicentre randomized controlled trial assessing the impact of a 'tailored lifestyle self-management intervention' (talent) on weight reduction. *BMC Obes* 2015;2:38.
- Melchart D, Wühr E, Weidenhammer W: High and low responders in a comprehensive lifestyle program for weight loss – secondary analysis of a randomized controlled trial. *Complement Med Res* 2017;24: doi:10.1159/000475663.
- Michaelis R, Niedermann C, Berger B: How can we enhance the sense of self-efficacy in epilepsy? Individual responses from 2 qualitative case reports. *Complement Med Res* 2017;24:doi:10.1159/000468986.
- Michaelis R, Schonfeld W, Elsas SM: Trigger self-control and seizure arrest in the Andrews/Reiter behavioral approach to epilepsy: a retrospective analysis of seizure frequency. *Epilepsy Behav* 2012;23:266–271.
- Lynning M, Hanehøj K, Karnøe Knudsen A, Skovgaard L: Self-care activities among people with multiple sclerosis in Denmark: use and user characteristics. *Complement Med Res* 2017;24:doi:10.1159/000478262.
- Büssing A, Poier D, Lauche R, et al: Validation of an instrument to measure patients' intentions and ability to change attitudes and behavior. *Complement Med Res* 2017;24:doi:10.1159/000477720.
- Berger B, Sethe D, Hilgard D, et al: Design of a self-management program for children aged 6–12 with type-1 diabetes mellitus at the Community Hospital Herdecke, Germany. *Complement Med Res* 2017;24: doi:10.1159/000479532.
- Baars EW, Koster EB, Verhoef J: The contribution of anthroposophic medicine to self-management: an exploration of concepts, evidence, and patient perspectives. *Complement Med Res* 2017;24:doi:10.1159/000478981.