



# Self-help friendliness: A German approach for strengthening the cooperation between self-help groups and health care professionals



Christopher Kofahl\*, Alf Trojan, Olaf von dem Knesebeck, Stefan Nickel

University Medical Center Hamburg-Eppendorf, Center of Psychosocial Medicine, Department of Medical Sociology, Martinistr. 52, D-20246 Hamburg, Germany

## ARTICLE INFO

### Article history:

Available online 1 July 2014

### Keywords:

Self-help groups  
Self-help organizations  
Self-help friendliness  
Patient involvement  
Participation  
Cooperation  
Quality management  
Germany

## ABSTRACT

Public and patient involvement in social and health care has proceeded in many civil societies. Depending on the legislations on national and community levels, citizens and patients have a greater say in shaping social and health care. In Germany, the patient involvement by self-help organizations at the macro level (national level and level of federal states) has significantly developed over the last ten years. At the meso level, however, the patient involvement is neither such far nor such systematically developed.

The concept of self-help friendliness (SHF) in health care is a patient centred model that allows the development and implementation of patient participation in different health care institutions: hospitals, ambulatory medical care, public health institutions, rehabilitation facilities etc.

In a series of projects on SHF we have (1) analysed the needs and wishes of self-help groups for cooperation with health care professionals as well as their experience, (2) gathered facilitators and barriers concerning the cooperation between self-help groups and hospitals, (3) developed a framework concept for SHF in hospitals including eight quality criteria for measuring SHF, and (4) implemented the framework of SHF in about 40 health care institutions ([www.selbsthilfefeundlichkeit.de](http://www.selbsthilfefeundlichkeit.de)).

Further projects followed: development of an instrument for measuring SHF in hospitals, integration of SHF-criteria in quality management systems in inpatient care as well as in out-patient care, and transferring SHF to a) medical ambulatory care, b) public health departments, and c) rehabilitation facilities.

Considering advantages and shortcomings of the approach, we can summarize that implementing SHF is feasible, transferable and a helpful measure for promoting patient centeredness in health care.

© 2014 Elsevier Ltd. All rights reserved.

## 1. Introduction

Amongst the various civil society organizations and associations there is a large field of self-help groups (SHGs) and self-help organizations (SHOs). The notion of self-help is used parallel to other notions such as patient and health consumer groups. A certain amount of such groups exists in nearly all countries, but their visibility varies widely (Hatch and Kickbusch, 1983; Baggott and Forster, 2008; Keizer and Bless, 2010). In Germany these organizations and groups have become increasingly involved at various political levels (local to national) in the governance of health care, mostly advocacy and evaluation, sometimes planning and delivery

(Schulz-Nieswandt, 2011; Trojan and Nickel, 2011a). Closely linked to these functions is their importance for quality improvement of the health care services as all of the mentioned features of involvement can be regarded as implicitly or explicitly aiming at improvements of the services according to the needs and interests of patients.

Already over three decades ago Levin and Idler (1981) described these third sector organizations (“mediating structures”) as a “hidden health care system”, arguing that their importance for the provision of services would not really be appreciated by health policy makers. Accordingly, one could address the impact of self-help associations in Germany as a “hidden health care improvement system”. This thesis is underpinned by a study with 345 SHGs in Hamburg, Northern-Germany, in 2003 (52% of all addressed SHGs in Hamburg; Trojan and Estorff-Klee, 2004, p. 66): 18% of the SHGs already participated in at least one quality improvement measure of health care professionals like quality circles, education

\* Corresponding author.

E-mail addresses: [kofahl@uke.de](mailto:kofahl@uke.de) (C. Kofahl), [trojan@uke.de](mailto:trojan@uke.de) (A. Trojan), [o.knesebeck@uke.de](mailto:o.knesebeck@uke.de) (O. Knesebeck), [nickel@uke.de](mailto:nickel@uke.de) (S. Nickel).

and training, user assessment etc., and further 40% were willing to do so.

Cooperation between health care staff and patient organizations is a crucial link between the professional and the “hidden health care system” and can be regarded as a concrete method to put a modern concept of patient centeredness, as defined by the Institute of Medicine (National Research Council, 2001), into practice. One of the identified four system components of health care quality is particularly relevant for our context: “Patient centeredness refers to health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.” (National Research Council, 2001, p. 7).

Despite the considerable amount of literature, very little has directly explored the role of SHGs and SHOs in health care improvement. There are grounded complaints about a general lack of self-help oriented research (Schulz-Nieswandt, 2011), specifically a need for more context-sensitive research (Kuhlmann and Annandale, 2012). The international literature is pre-dominantly focussing on other roles and functions of patient organizations (cp. Landzelius and Dumit, 2006), in particular as a challenge for the medical system (Kelleher, 2006), as a social movement (Allsop et al., 2004), as an approach to democratize the health care system (Box, 2009; Lofgren et al., 2011), or as first attempts to establish cooperative alliances between the “lay care system” and the formal health care system (Borkman, 1990; Kurtz, 1990). The agreement about the importance of such alliances has grown considerably (Goldman and Lefley, 1996; Mackay, 2004; Akrich et al., 2008; Baggott and Forster, 2008). However, the debate on potentials, shortcomings and roles of SHGs and their collaboration with health care professionals within the present health care provision is still going on (Forster and Gabe, 2008; Cowden and Singh, 2007).

In Germany, the term “self-help friendliness” (SHF) has become a popular expression for more openness of health care institutions to cooperation with SHGs of chronically ill patients (Trojan et al., 2011; Fischer et al., 2004). In our contribution we will present and discuss the development of SHF as an approach for cooperation based on a “partnership model” (Rabeharisoa, 2003). Rabeharisoa’s model was basically used for participation of patient organizations in scientific research. We believe it to be equally relevant for our approach as its main characteristics are: “(i) the patient organisation is master of its research policy; and (ii) patients are specialists’ partners in their own right” (Rabeharisoa, 2003, p. 2131). These requirements for a ‘true’ partnership apply in a similar way to SHF. Looking for the impact of civil society organizations on the provision of health care services we will explore, what we may expect from this approach and which shortcomings it has for the future.

## 2. Background: self-help terminology and recent developments in Germany

In Germany ‘self-help’ is used as a proxy term for any activity of collectives of patients or citizens dealing with specific social, political, environmental or mostly health related topics. Self-help is covering small regional support groups up to big and more or less professionally organized SHOs aiming at political influence and lobbyism. In the following we will stick to the term ‘self-help’, distinguishing between SHGs (mostly regional, face-to-face) and SHOs (health consumer and patient organizations, umbrella organizations or alliances, pressure and lobby groups etc.).

The more recent boom in social and civic engagement of patients in form of SHGs can relatively clearly be dated to the 1970s and early 1980s (Geene et al., 2009). The process of their growth and political acknowledgement was significantly driven by a large

research program of the former German Federal Ministry of Research and Technology from 1979 to 1983 (Kofahl, 2010). In the dynamics of civil society development in the last 30 years, self-help produced manifold forms of activities, involvement and self-help concepts (Matzat, 2006–2007). The number of SHGs increased up to 100,000 with approximately 3 million members (about 3.5% of the German population) (NAKOS, 2009), and has settled down on a more or less stable level for nearly two decades now. The life time prevalence of SHG attendance is about 8.8% (Gaber and Hundertmark-Mayser, 2005; Kofahl et al., 2011).

At a higher organizational level, there are clearly above 1000 SHOs on regional, federal and national levels. Just on the national level there are more than 300 SHOs which can be assigned to health related issues, from addiction to psychic disorders, and from widespread chronic conditions or disabilities to orphan/rare diseases. While specifically the latter ones can be rather small with less than a hundred members – even at the national level – others are reaching several thousands of members. In addition, the self-help sector is supported by a nation-wide self-help supporting system consisting of about 280 self-help clearinghouses plus 40 smaller self-help offices. Self-help clearinghouses are professional community counselling services for the support of self-help. Staff is usually qualified in social work. The landscape of self-help associations in Germany is summarized in Fig. 1.

Meanwhile, the field of self-help is fairly integrated in Germany’s health care system and regulations rather than a distinguished stand-alone sector. Very briefly described, the following milestones were crucial for this advance:

- a) 1999 – The deputies of the federal health ministries decide for a formal recognition and integration of patients in health care policies.
- b) 2004 – Health care system reform (Social Security Code Book V):
  - § 140 f: participation of patients in the ‘Joint Federal Committee of Physicians and Statutory Health Insurances’ for decisions on the catalogue of benefits of the Statutory Health Insurances (today’s volume: almost 180 billion Euros); patient representatives have the right to discuss and to comment on decisions. However, they do not have formal voting rights.
  - § 140 h: a national ombuds-person for patients, appointed in order to care for the rights of patients in political decisions.
  - § 20 (4): Statutory Health Insurances are to give 0.53 € per insured person for self-help promotion (before this legislation they could give the named amount, however, the expenses were only about 30%; with the revised § 20 (4) the expenses increased to around 70%, but still did not reach 100%).
- c) 2008 – Health Care system reform (Social Security Code Book V): New § 20c – Statutory Health Insurances have to give 0.53 € (with yearly increase) per insured person for self-help promotion (expenses of 100% now, approx. 40 million Euros in total, which sounds much, but is only 0.02 percent of the statutory insurances’ total health care expenses (Trojan and Kofahl, 2012)).

Patient involvement proceeded at the level of the federal states as well. Patient representatives are participating in planning and decisions of local authorities, state ministries, physicians’ chambers and the regional Associations of Statutory Health Insurance Physicians. In several areas they are given voting rights. Patient representatives are also involved in guideline-development within the professional medical or care associations (Matzat, 2013; Sanger et al., 2009). Through these developments three main concepts

متن کامل مقاله

دریافت فوری ←

**ISI**Articles

مرجع مقالات تخصصی ایران

- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان دانلود رایگان ۲ صفحه اول هر مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات