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# Patient-Centered Medicine and Self-Help Groups in Germany: Self-Help Friendliness as an Approach for Patient Involvement in Healthcare Institutions

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Additional information is available at the end of the chapter

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## Abstract

Collaboration between laypersons and professionals is closely linked to the concept of patient centeredness. Patient centeredness means meeting the needs of *individual* patients as well as reacting to patients' demands on the *collective* level. The support of self-help groups and their integration into healthcare institutions represent a major policy approach to fulfilling this requirement. Here, we first deal with the concept of patient centeredness in general, and the understanding of concept and use in Germany. We also provide a short definition of self-help friendliness (SHF) and discuss the success achieved in implementing it in Germany so far. We then clarify the closely related concepts of patient centeredness, patient participation and patient involvement SHF is seen as a strategy for increasing both patient centeredness and patient participation in healthcare services. We subsequently describe the involvement of self-help groups and patient associations in a series of empirical studies and practice-oriented projects carried out between 2004 and 2013. The last section contains a general discussion of the SHF approach as a means of systematically increasing sustainable patient centeredness and patient participation in healthcare services. Finally, we address the chances for future development in Germany and the transferability of SHF to other countries.

**Keywords:** self-help friendliness, self-help groups, patient centeredness, patient involvement, patient associations, healthcare institutions, healthcare research

## 1. Introduction

The backdrop to this chapter was the development and implementation of the concept of “self-help friendliness” (SHF) in Germany. This process started in 2004 and has good chances and prerequisites to be continued in the coming years. The idea behind is based on a number of expert opinions, surveys and well-documented model projects. Parallel to this practice-oriented developmental research, from 2008 to 2011, a research project with the title “Self-Help Friendliness as a Quality Concept” was carried out. The project was funded by the German Federal Ministry of Education and Research (BMBF) as part of a larger project in the BMBF’s research framework program “Chronic Diseases and Patient Centeredness”.

This chapter deals first with the role of SHF as one of the main elements in patient centeredness as well as its role in the overall German healthcare context. Thereafter, we concentrate on looking at the research and practical experiences gathered with the idea of SHF as well as outlining the present state of the concept’s implementation in healthcare facilities.

## 2. Patient centeredness as a guiding concept

Providing a precise definition of and an approach to the concept of patient centeredness is challenging. Patient centeredness is no longer just a matter of treating patients in a “humane” manner; the concept has become very complex because of the fact that patients today are also evaluators, controllers, critics and active contributors to the development and regulation of the healthcare system.

This abandons any simple understanding of patient centeredness. However, until today the German Medical Association as one of the most important players in the German healthcare sector reduces patients’ roles to more or less inactive recipients and beneficiaries. Their guideline on quality management in hospitals can be seen as an example how the term “patient centeredness” can be narrowed down to a number of unidirectional features of professionals towards patients, but not vice versa:

- “waiting times during admission to the hospital,
- receiving proper information during the doctor’s visit,
- extent of care provided by nursing personnel,
- waiting times during X-rays, endoscopic examinations, laboratory exams, etc.
- handling of privacy concerns,
- wake-up and bedtime hours,
- contacts with social services,
- number and types of leisure programs,

- hygienic measures,
- guidance in the hospital, access to the parking lots and other means of assisting patients and visitors who enter the hospital" ([1] p. 45).

No doubt—all of these points are important. Nevertheless, the guideline gives the impression that the managers of health facilities knew in advance of how their organizations work and how their offers should be structured to ensure patient centeredness—and thus that they require no input on the part of the patients: "Patients trigger the demand for orientation, and the personnel takes the proper action" [2].

Even in differentiated and focused papers on patient centeredness in Germany, the contribution of the *active* patient in the concept of patient centeredness remains at least vague or is even completely absent (e.g., [3–5]).

A contemporary understanding of patient centeredness, however, demands just such active participation. Patient centeredness ought to balance the informational asymmetry between professional staff and patients and promote equitable interactions. It is not just a matter of sharing knowledge; also, the responsibility for therapy and diagnosis has to be distributed ensuring a reciprocal process to replace the former domination of the physician's perspective. This in turn demands great sovereignty and responsibility on the part of the patient [6]—not only on the microlevel of healthcare provision. It is a transforming perspective from the patient "who is cared for" to the patient who is an "active participant," and an active "creator of the treatment process" [7], and indeed of the entire provision of health and social services [8].

In 1995, the PubMed/Ovid MEDLINE system introduced the Medical Subject Heading (MeSH) term, "patient-centered care", defined as "design of patient care wherein institutional resources and personnel are organized around patients rather than around specialized departments" [9]. In 2001, the Institute of Medicine defined "patient centeredness" as: "health care that establishes a partnership among practitioners, patients and their families (...) to ensure that decisions respect patients' wants, needs and preferences and that patients have the education and support they require to make decisions and participate in their own care" ([10], p. 7). In his conclusion, Blum [11] summarized the concept of "patient-centered care" with the key-terms integration, information, communication and participation. Self-help-oriented patient centeredness corresponds to this modern definition by focusing on the cooperation of self-help organizations with professional services.

The International Alliance of Patients' Organizations (IAPO) did a systematic study to determine what patient centeredness looks like around the world [12]. Not surprisingly, they found many and manifold different definitions, which, however, have despite of their diversity very similar core statements. The definition supported by the IAPO is comparable to that of the Institute of Medicine [10]. In a declaration on patient-centered health care derived from that overview ([12], p. 29), the following five principles are given:

- respect
- choice and empowerment

- patient involvement in health policy
- access and support
- information

This understanding of patient centeredness is clearly reminiscent of the term “health literacy” propagated by the World Health Organization [13] as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”. In this sense, patient centeredness is a continual companion in the endeavor to increase the health literacy of all citizens in general and patients in particular.

The concept of SHF runs parallel to the approaches put forward by the IAPO and the WHO. One of our original propositions is that the implementation of modern approaches to patient centeredness demands cooperation with self-help groups (see [14–16]). This thought is present in the newer secondary literature on patient centeredness, but does not play a prominent role in the light of the many other aspects of patient centeredness. Unfortunately, the various potentials for implementing self-help in patient centeredness have to date not been fully realized but often reduced to individual functions. Here, some German examples:

- classifying the complaints of self-help organizations as “patient feedback” ([177], pp. 62–63),
- regarding them as “complementary services” or as “complementary efforts” ([18], p. 25),
- relaying information on self-help groups during discharge procedures ([18], p. 19),
- “Using experiences of self-help” by allowing “persons concerned to assist in disseminating information to patients” ([17], p. 66),
- cooperation subsequent to hospitalization [18].

These forms of cooperation are oriented towards the short definition of patient centeredness as the “adjustment of available services and operating procedures to the presumed interests and needs of patients” [18].

More recently, the idea of participative (or shared) decision-making has played a major role. This thrust exists primarily in the individual doctor-patient relationship on the microlevel, from the patient vantage point as “co-production,” and in the interactive process of decision-making [19]. In fact, however, there are a number of recent programmatic articles proposing a broader and more diverse understanding of cooperation. Some of the early demands and present opinions are reflected in the following research papers:

- Patients as “an important resource in the fight against ignorance, quality defects and waste in the healthcare system” [20].
- Quality is a utilitarian approach—meaning participation, i.e., “patients and insured persons are involved in decision-making processes at all levels through their position as users” ([21], p. 78).

- “We must give consumers of the healthcare system a voice and enable a dialog between them, the providers and the political system” ([22], p. 25).
- “Support for organized self-help is an area of activity that serves to strengthen citizen and patient centeredness” ([16], p. 24).
- The goal is to use the “collective competence” of self-help to influence new directions taken by caretaking structures and procedures, and generally to strengthen the skills of patients ([5], p. 1120).
- “Human relations should include and support all forms of self-help” ([17], p. 72).

The last quote refers to “patient-centered quality management” [17], which holds the promise of becoming a context for including cooperation with self-help groups in a less random way than offered by previous well-meaning but weak contacts.

The first important document that brought patient centeredness into the mainstream as a goal of continual quality management was an application developed in 1996 during the Conference of Health Ministers of the Federal States of Germany [23]; later found in the concordant application with the National Expert Council in Health Care [24]. At that meeting, “goals for a common quality strategy in the healthcare system” were adopted, the first goal being “systematic patient centeredness in the healthcare system”.

The document clearly shows that concepts concerning patient centeredness and patient participation in the healthcare system are closely related with quality assurance strategies. To date, this has been realized to a greater extent for the macrolevel of the healthcare system [16] than for the mesolevel of individual institutions such as hospitals and physicians’ offices ([25], p. 19).

Implementing a comprehensive plan for patient centeredness is greatly dependent on how sound the systems for quality management and quality assurance have been established. Groene et al. [26] did a Europe-wide study of hospitals concerning the relationship between patient centeredness and the presence of quality management: patient centeredness was more broadly implemented in hospitals with an extensive quality management.

Good quality management on its own, however, does not necessarily guarantee an implementation of patient centeredness—neither is it a predictor of systematic cooperation with self-help organizations. In addition to quality management, “proper overall conditions are necessary that allow those professionals working in the healthcare system to take patients into due consideration, in particular, by focusing on their wishes and preferences,” as was formulated in the conclusion of the “Report on Citizen and Patient Centeredness in the Healthcare System” ([16], p. 26).

This short overview of the German situation serves to point up deficits and to provide suggestions on establishing cooperations with self-help groups. In our opinion, the concept of “self-help friendliness of healthcare services” comprises quite a number of advantages for patients and healthcare providers and should be integrated in a modern understanding of patient centeredness. During the course of implementation in Germany, some important milestones have been achieved:

- The basic principles of cooperation with organized self-help groups were systematically reduced to a manageable list of just seven quality criteria.
- Specific criteria were adapted to the individual areas of healthcare (inpatient, outpatient, public health, rehabilitation).
- The criteria for all areas were jointly formulated by healthcare professionals—predominantly those, who are responsible for quality management—representatives of self-help organizations, and professional staff of the self-help clearinghouses. The criteria represent the interests and needs of both the collective group of patients and their self-help representatives and professionals in the respective positions.
- Implementation was tested in all areas, systematic approaches were developed, and the concepts and experiences derived from these attempts were put at the disposal of all facilities involved ([www.selbsthilfefreundlichkeit.de](http://www.selbsthilfefreundlichkeit.de)).
- The quality criteria comprise three main dimensions: (1) a coordinated cooperation based on information and support for the self-help groups; (2) the dimension of participation through information exchange, participation in the further education of staff, as well as participation in bodies such as quality circles and ethics committees; (3) the long-term assurance of communication and cooperation (sustainability). The completeness and applicability of these criteria were evaluated in a number of surveys and with various groups of participants [27, 28].
- The consistent application of these criteria leads to an overall increase in the systematic participation of organized self-help on the mesolevel. The participation of patients is generally accepted, but to date has not been realized in reforms of the healthcare system.
- Overall, this approach highlights previously neglected aspects of patient centeredness and cooperation with patient lobby groups. It demonstrates ways in which these aspects can be solidly integrated into quality management, both at the level of individual facilities and on the system level.

As the advantages of SHF discussed in this section are rather abstract so far, we will strive to present the relevant aspects in clearer and concreter terms. The next section systematically focuses on the relationship between the three main programmatic terms patient centeredness, SHF and patient participation.

### **3. On the relationship between patient centeredness, self-help friendliness and patient participation**

Patient centeredness, SHF and patient participation are concepts with rather fuzzy borders. Presently, there are no agreed-upon scientific definitions. At least, the fact that these three terms represent the key concepts for creating healthcare that is tailored to patient needs and requirements, and thus likely also suited to ensure economic effectiveness, is globally accepted [29–38]. Internationally, there are a number of different approaches, methods and regulatory instruments for integrating patient participation into healthcare systems [39–43].

In Germany, the development and implementation of these concepts has gone hand in hand with the overall rise of the self-help movement and for some time has been subsumed under the catchword “Self-Help Friendliness”. The only other similar country in this regard is Austria, which established a similarly important role for self-help within its healthcare system [44, 45]. Three factors in particular can explain the present development in Germany: First, there is a well-established landscape of self-help organizations and up to 100,000 self-help groups with around 3–3.5 million members. Second, this development has been supported systematically for several decades now [46], especially, by Para. 20 h of the Social Security Code, Book V, which requires that the statutory health-insurances companies pay EUR 1.05 per insured person to promote self-help, which sums up to around 73 million EUR. (This amount is changed every year to reflect cost-of-living increases). Third, since 2004, the German government has adopted a policy whereby patients (including for the most part the representatives of self-help organizations) are increasingly being included in the future planning of the healthcare system at the macrolevel.

Yet systematic cooperation between physicians and self-help groups as a way to increase patient participation as well as the quality of healthcare provided has barely been addressed in the international research literature. For this reason, we must rely on the ongoing discussion in Germany to determine the relations among the various different concepts.

It is helpful to differentiate between a broader and a narrow employment of the term patient centeredness. As mentioned at the outset, patient centeredness basically comprises everything that is carried out or improved upon within a healthcare facility to affect patient care. In accordance with the popular slogan “The Patient Is the Focus of Our Concerns,” patient centeredness becomes nearly synonymous for comprehensive quality management.

The narrow understanding regards everything that directly concerns cooperation with patients and their welfare as belonging to patient centeredness. The broad understanding also includes the two components that make up this concept: “internal” and “external” patient centeredness [47]. *Internal* patient centeredness reflects all interventions that deal with the structures and processes occurring within a hospital which serve the well-being of the patient; *external* patient centeredness concerns everything that is in direct contact with patients and occurs in cooperation with the patient. This understanding of patient centeredness may also be seen as the invitation directed towards the patients to participate in the processes of professional caretaking.

The participation of the patients may be further divided up into different levels of intensity. Participation may reflect only “joint knowledge” (strengthening one aspect of health literacy), to “having a say” (participation in the relevant boards and committees) or up to “codetermination” (participation in the decision-making process and active voting rights in boards and committees).

All three basic concepts—patient centeredness, participation and SHF—are employed on all three levels: physician–patient interaction (microlevel), the institutional level of the individual facility (mesolevel) and on the system level of the entire healthcare system (macrolevel).

This chapter is concerned mainly with the mesolevel and the associated question: How can we create and anchor more SHF (and thus greater patient centeredness and participation) in the facilities of the healthcare system? We used an instrument from our research project to measure “self-help-related patient centeredness.” This concept comprises two components: (1) strengthening *individual* self-help competences (How intensively does the hospital support individual patients by informing, enabling and including them in caretaking processes?); (2) strengthening *collective* self-help efforts (How intensively does the hospital cooperate with self-help groups in accordance with quality criteria?).

Within the context of this volume on patient-centered medicine, we barely touch on the microlevel and the macrolevel. Rather, our focus lies clearly on the *collective patient centeredness* on the mesolevel, that is, initiating cooperation between local health facilities and collective self-organized patient groups. SHF is considered one special aspect of the quality dimension “patient centeredness.” SHF is only shortly discussed by us on the macrolevel, in particular when we are concerned with SHF in quality management systems (in this context: the so-called accreditation systems) and in the coordination of SHF at the national level (“Network Self-Help Friendliness and Patient Centeredness in the Healthcare System” [48]).

## 4. Developing the approach

The development of self-help friendliness did neither follow a “master-plan” nor a rigorously designed intervention concept. The process should rather be considered as a complex participative research program, which has been described in a recent publication more comprehensively [49]. The development comprised a number of empirical surveys and practice-oriented demonstration projects. All these projects were conducted between 2004 and 2013 (see **Table 1** [49]). Their methods differed considerably: most often qualitative (expert interviews and focus groups) and quantitative surveys were combined. As a guiding principle, patient representatives contributed in several stages of the research. Due to the participative approach, we proceeded only step by step. The core elements of self-help friendliness became continuously clearer by discussing the relevant quality criteria in the various sectors of health services. The implementation in one sector inspired and facilitated the process in the following ones. There was a steering group of professional self-help supporters, social scientists and staff from both sickness funds and healthcare providers, who looked for funding and decided on how to proceed. One milestone was the foundation of a network on SHF in 2009 (see Section 6.3). In its first years, the network consisted primarily of actors who had made major contributions to the support of self-help groups (SHGs) in various contexts and had promoted their recognition in practice and politics of healthcare provision. They favored a more systematic approach to sustainable collaboration between SHGs and healthcare professionals and were willing to find and/or to provide resources for implementing SHF. Particularly, healthcare insurance companies funded a number of both model projects and research. The steering group of healthcare insurance representatives and a professional self-help supporter have been the driving force for further development till today. They are

supported by a “federal coordination office” funded by a consortium of four sickness funds [48].

Study area (year)	Type of study	Sample	Main results
Hospital, part 1 (2004/2005)	Explorative survey	30 SHO, 20 SH clearing houses	Participative development of criteria
Hospital, part 2 (2004–2006)	Model project, implementation study	2 hospitals in Hamburg	Testing and final formulation of 8 criteria; 2 hospitals awarded “quality seal”
Hospital, part 3 (2008–2010)	Model project, implementation study	31 hospitals in NRW, 17 finishing the process	Process pattern and guidelines for becoming self-help friendly; 17 hospitals awarded distinction
Public health service (2009–2011)	Delphi method, interactive identification and approval of quality criteria	16 public health departments	10 quality criteria approved by workshop of public health doctors at their annual conference 2011
Ambulatory care (2009–2011)	Model project, implementation study	9 practices, individual MDs from 8 specialties	6 criteria approved and introduced into quality management manual for doctors in NRW
Rehabilitation (2010–2013)	Model project, implementation study prepared by focus group of 14 SHR	2 rehabilitation hospitals	5 criteria successfully tested; 2 hospitals awarded distinction; introduction in one national accreditation system planned

**Abbreviations:** SHO, self-help organization; SH, self-help; SHR, self-help representative.

**Table 1.** Major studies and steps in the development of SHF [49].

#### 4.1. Development of self-help friendliness in hospital care

The concept of SHF stems from two sources. The first is a former survey of 345 contact persons out of 658 SHGs in Hamburg. As a main result of this research, it became clear that most SHGs were not satisfied with the care they have received. Consequently, they wanted changes both in the attitudes of their healthcare providers and in the running of healthcare institutions. These results were interpreted as a plea for intensified communication and collaboration between SHGs and professional staff in health services. Self-help friendliness was the most systematic approach to reach this goal.

The other source and stimulus for this approach were the annual “self-help forums”, a sort of workshop of SHG members and medical doctors of all specialties. They are regularly organized by the Medical Chamber of Hamburg in collaboration with the local clearinghouse for SHGs. In the course of a discussion about shortcomings of hospital care, the idea of “self-help friendly hospitals” arose. It was appealing to both parties, doctors and self-help members. In 2003, this term resulted the first time in a formal cooperation statement between the Federation of Hamburg State Hospitals and SHGs. At the same time, the idea came up to initiate and to evaluate the implementation of the approach in some pilot hospitals. The funds for an

explorative study and the process evaluation of the model project were granted in autumn 2004 from the Federal Association of Company Health Insurance Funds (BKK BV).

The explorative study started in 2005: A questionnaire was sent to self-help organizations and self-help clearinghouses with extensive experience in cooperation with healthcare providers, SHGs and SHOs, and patient representatives. About 30 organizations and 20 self-help clearinghouses administered the questionnaire. They responded to questions concerning their wishes and expectations and assessed several statements on quality criteria that had come up so far in the self-help forums. These assessments provided a first quantitative picture of what was important for self-help groups and, hence, what they would prefer to be implemented. This was the first basis for the identification and formulation of those quality criteria that were adopted in the end.

A steering group of the model project decided for the relevant criteria. The group comprised a project leader (a former self-help supporter with know-how in quality management), three hospital quality managers, two employees of the local clearinghouse and four members of SHGs. Staff members of the Hamburgian Institute of Medical Sociology accompanied the process as consultants. Eight criteria for good collaboration between hospitals and SHGs were developed [49]:

1. The hospital offers rooms, infrastructure and possibilities for public relations.
2. Patients of the hospital are personally informed about self-help on a regular basis.
3. The hospital supports public relations of the SHG.
4. The hospital appoints a staff member as a contact person for self-help.
5. Staff and SHG members meet regularly for information exchange.
6. SHGs are involved in further education/training of staff.
7. SHGs are involved in quality (control) circles and ethics committees.
8. The collaboration is formally agreed on and the activities will be documented.

Most of the criteria address the support of SHGs by the hospital; criteria 5–7 aim at a permanent and regular involvement of SHGs in the health service quality.

The implementation of self-help criteria was achieved in two hospitals in a process of nearly two years. Thus, the “reality-test” of the quality criteria was passed successfully. As a reward (and as an incentive for their further engagement), the two hospitals were awarded a “Quality Seal for Self-Help Friendliness” in 2006, based on an external audit. Eight members of SHGs, who had been trained for this task, played a major role in the on-site Visitation. The quality criteria were published in their final version as a brochure guiding and encouraging both hospital staff and self-help advocates in other places to do the same.

The process as a whole, however, had to face several delays due to lack of funding. Finally, the welfare organization “Der PARITÄTISCHE North Rhine-Westphalia” provided resources for the next development project from 2008 to 2010. This model project had the aim to develop a

standard for the consecutive steps of implementing the quality criteria in hospitals, which resulted in nine steps of becoming “self-help friendly” [49]:

1. The agency for SHF (or a self-help clearinghouse) contacts and informs the hospitals.
2. First consultation of the agency takes place in the hospital.
3. The agency contracts the hospital and mediates contacts with self-help clearinghouses.
4. The staff of the self-help clearinghouses counsel hospital staff and mediates SHGs.
5. The hospital and SHGs collaborate in a quality circle.
6. Measures to fulfill the quality criteria are put into practice and are part of the internal quality management system.
7. The hospital applies for a certificate (optional).
8. The quality report of the hospital is signed by representatives of SHGs.
9. Certification (formally documented distinction) is awarded and can be used in public relations of the hospital.

Thirty-one hospitals in North RhineWestphalia (NRW) made use of the offered supportive consultations. Seventeen finished the implementation of SHF with a distinction in the form of a certificate. The capacities of the experienced facilitator for becoming self-help friendly (a half-time social worker), however, turned out to be overstrained: She did not have the resources and capacities to meet the total amount of requests for support, which means that probably more than the mentioned 17 hospitals might have finished the process if more resources were available.

The projects in Hamburg and in NRW produced decisive findings and downloadable guidance for other hospitals interested in becoming self-help friendly ([www.selbsthilfefreundlichkeit.de](http://www.selbsthilfefreundlichkeit.de)). There were, however, some problems that obviously had to be conceived of as obstacles for further spreading the approach: For example, providing additional staff for consultations, as it was carried out in the model project during the implementation process, was too expensive. Consequently, the approach was changed in the sense, that near-by clearinghouses get a small amount of funding in order to compensate them for their additional workload. A formal quality seal after an external audit, which in the first project had seemed the most appropriate way to give an award, required too many resources, too, both human and (ultimately) financial: The expenditure of time was enormous, not only for the hospitals but also for the self-help representatives. Presently, healthcare services can gain an award of the network “Self-Help Friendliness and Patient Centeredness”. Prerequisites are (i) a certification by patient representatives that at least one measure for each quality criterion was put into practice and (ii) the inclusion of the SHF quality criteria in the internal quality management system. These two simple requirements are easy to fulfill, and additionally guarantee that no advertising of SHF claims can be made without the consent of the collaborating SHGs.

#### **4.2. Development of self-help friendliness in other areas of the health services**

After successful implementation in the hospital area, the program was started in the other healthcare sectors: public health, practices and rehabilitation services.

The process in the area of public health did not correspond to the general pattern because the ten quality criteria stem from an interactive process with professionals from 16 public health departments of local health authorities. Unfortunately, we do not have exact data on the degree of local self-help engagement.

The next project started to develop equivalent criteria for ambulatory care. The ten existing recommendations for cooperation and the eight quality criteria for inpatient care can be seen as the starting point for developing criteria for outpatient care in an interactive process of all relevant players. They produced a consensus document with six criteria that was accepted by the Association of Statutory Health Insurance Physicians Westphalia-Lippe. These criteria are quite similar in substance to those in the hospital sector.

Nine practices (doctors with their staff) participated in the process: general practice, gynecology and obstetrics, internal medicine, urology, ophthalmology, orthopedics, ENT medicine and pediatrics. At the end of the process, in which the medical and lay persons jointly developed measures to put the quality criteria into practice, the implementation of the criteria was formally documented in a report which was signed by both parties. The practices were subsequently awarded as being self-help friendly. Current endeavors are underway to build doctors' networks (instead of single practices) as partners in this process.

The way in hospitals for rehabilitation was similar to the hospital sector. It started with a team on quality assurance of an umbrella organization of rehabilitation institutions. In December 2011, the preliminary SHF criteria were discussed with 14 self-help representatives in a workshop. Result were five quality criteria which were tested in a pilot project with two rehabilitation hospitals. The participating SHGs in the project were: the Interest Group of Contergan Victims, the Federal Osteoporosis Association, the German Multiple Sclerosis Society and a local SHG of stroke patients. Finally, the successful implementation of SHF was proved by self-help representatives and led to a distinction for the hospitals involved.

### **5. Research limitations and transferability to other countries**

It is not possible to discuss in detail the research limitations of all the mentioned pilot projects and studies. But, we would like to highlight some basic problems, both of which have been discussed in a previous medical sociological publication [50].

One of the most important features of the different studies is their participative and explorative nature. This has obviously some disadvantages: Despite all attempts to gather information as systematically as possible, and to reflect all aspects of the development, implementation, testing and evaluating of SHF, the results are not representative, neither for all healthcare professionals nor for all self-help representatives. Participants are usually highly motivated,

therefore the results are emphasizing much more the positive factors rather than potentially negative ones. All generalization of these experiences and results is only adequate in comparable contexts with healthcare institutions which are open towards SHF and patient centeredness.

The very essential issue whether SHF is feasible *at all* in healthcare institutions can be answered positively. This implies that SHF criteria have been integrated into the quality management system of healthcare institutions and thus have become sustainable.

However, another question is the transferability to other countries. Though there are many other types of collaboration with patients [51], we only know about comparable approaches in Austria. This seems to be grounded in similarities both in the hospital sector and in the policies to promote and integrate self-help associations. Firstly, of course, due to the common language, which makes it much easier to adopt ideas and concepts, and secondly because of a regular exchange between Austrian and German members of relevant advisory boards. Regarding to the first German pilot project in Hamburg, similar initiatives of SHF have been put into practice in about 40 Austrian hospitals [44]. This confirms the transferability in comparable contexts.

## 6. Discussion and conclusion

### 6.1. Advantages of the concept

Cooperativeness is a necessary but not sufficient prerequisite for better involvement of civil society organizations into quality improvement of healthcare services. The SHF concept and its implementation offer some incentives, such as the formal acknowledgement, either as a “seal” for promotion and corporate identity or as a quality certificate in the framework of a quality management audit [52].

The additional practical support by counselors from the agency for SHF and the involved clearinghouses on self-help assist hospital staff and SHG members to find practical solutions for systematic implementation of collaboration. The open concept of patient centeredness and the “romantic vision” of a doctor-patient partnership turn into a measurable task. This intensifies the pressure to produce a positive result: Failing is visible and may be embarrassing.

Further advantages are several (positive) side effects which are coming up for both partners [50]:

- If a hospital decides for the SHF approach, this has to be communicated to patients. This leads to an overall reflection of questions like: ‘What is self-help at all?’, ‘Is self-help beneficial or can it bear risks?’, ‘Can I recommend it to my patients and, if so, how shall I communicate it to them?’
- If SHGs decide for the approach, they will have to fulfill additional roles, and the “voluntary”-aspect of their work may become subordinated. Other questions arise: ‘How do we define our (new) roles?’, ‘How do we make sure

that we are complementary to professional staff and are not regarded as a substitute?', 'How do we deal with dissatisfaction or conflicts between hospital patients and hospital staff?' etc.

In the whole, we can summarize that the discussion about and reflection of the topic "SHF" helps ...

- to inform healthcare professionals about the role, chances and possibilities of self-help and specifically their integration in professional care,
- to clarify the roles and responsibilities of healthcare staff and members of SHGs,
- to better understand the viewpoints and needs of their counterparts,
- to learn new facets of the relevant indication and their implications for coping, self-management and consequences in daily life.

These are all relevant aspects of (collective) patient centeredness which can measurably increase the quality of care in terms of health outcomes [53], better functional status, less infections, shorter hospital stay and higher compliance in joint replacements [54], or significantly reduced decubitus rates and other treatment-related complications [55]. Hospitals and quality managers like the effect that patient centeredness even can reduce the costs and thus increases the financial benefit [31].

There is some evidence that SHF is a solution to the lack of sustainable cooperation and a way to enhance quality standards in patient-centered care. There are signs that this results in better patients' health outcomes. Nevertheless, there is a strong plausibility that healthcare institutions will re-adapt their procedures to patients' needs and thereby improve patient satisfaction, self-management, coping and health literacy. Forster and Rojatz ([44], p. 50–51) scientifically accompanied the SHF-implementation process in Austria with a qualitative study design. They found some reasons why the approach is appreciated and accepted. Positive effects were mainly seen in the quality of cooperation with patients, better visibility and acknowledgement of SHGs, as well as an increasing patient centeredness in hospitals. Interestingly, the interviewed experts did not see any disadvantages. A qualitative study in Germany found strong agreement of both professional staff and SHG-members that SHF would enhance quality in care [56].

## 6.2. Shortcomings of the concept

We should not ignore that the voluntary engagement of SHG members can be rather limited due to their health conditions or even may stop suddenly because of decompensation or acute episodes of their illness [57]. Furthermore, healthcare organizations or legal committees require more and different skills beyond the "mere patient role". Just being a patient who is only describing his or her experience, but not reflecting the wider circumstances and the impact on healthcare providers, institutions, regulations and legislation, may not be sufficient for the concerted development of common strategies [58]. Finally, the motives of the different stakeholders addressing SHGs can be very different. SHGs seem increasingly to be a target of

other actors in the health policy arena, like healthcare insurers or especially the pharmaceutical industry [59], but also scientists, predominantly in the area of medical research.

The study with 625 moderators of physicians' quality circles showed that doctors considered a possible relief of their workload as one of the strongest incentives [60]. However, there is a high probability that professionals like to establish patient groups as auxiliaries [61] rather than equal partners. Several scientists have expressed their concerns about such kinds of "misuse" and identity changes of patient groups; they argue professionals would offer collaboration but in fact try to get "control" of SHGs [62] or to achieve "colonization" [63–65].

Rabeharisoa's "partnership model" [61] should hinder misuse and legitimate SHGs to adjust any aberrations from SHF as it is meant by its proponents, if this concept is truly understood and adequately put into practice. However, also here, the above described risk remains: Professionals might take personal advantage of SHGs or could try to co-opt them.

### 6.3. Future development in Germany

The SHF approach is focusing at one global aim, which is to reach quality improvements in health care by promoting both individual and specifically collective patient centeredness. While at the *macro* level patient representatives and other stakeholders in the healthcare system mostly negotiate legal and administrative quality issues, SHF at the *meso* level deals significantly more with daily routines and practical issues in treatment and care. One crucial requirement can be seen in positive attitudes and mindsets of professional staff towards SHGs, which is not a matter of course, as still today some reservation against SHGs exists. Thus, SHF is also a continuous change management process.

The German Network "Self-help Friendliness and Patient Centeredness" promotes a nationwide cooperation between healthcare professionals and SHGs by developing and circulating training materials, implementing agencies for the support of SHGs, running pilot projects, and integrating self-help-friendly criteria into quality management and accreditation measures ([www.selbsthilfefreundlichkeit.de](http://www.selbsthilfefreundlichkeit.de)). This network helps to tackle critical and non-desirable developments at an early stage, and it can deal with new ways and opportunities for dissemination. These are reaching from appropriate incentive structures to demonstration projects aiming at the implementation of patient centeredness and/or SHF in institutions [36, 39, 43].

The German network has grown steadily since its start in 2009. In April 2016, the network consisted of 118 active members, 42 of them were local self-help clearinghouses, 13 were sent by self-help organizations, 29 were coming from hospitals, and 16 from rehabilitation hospitals. Twenty-one general hospitals and 5 rehabilitation centers are currently distinguished as self-help friendly healthcare institutions. In each case, the list contains the names of the collaborating SHGs (about 9, on average; [66]). If we keep in mind that *active* dissemination is still in the beginning, these figures look promising.

### 6.4. Potential and barriers for international transfer and dissemination

Patient involvement and participation in health care and the ways and methods to integrate them in health policies vary in different countries. Despite comparable aims and principles in

general, it is still difficult to compare these developments cross-nationally due to diverse and permanently transforming national healthcare systems [67]. At least for the Western World, we meanwhile can assert that there is a common agreement for the need of patient centeredness and patient involvement. We can also state that the reluctance and resistance of healthcare professionals against patients and SHGs, which has often been observed and discussed in the past [68], has more or less overcome. Nevertheless, it is still quite challenging to transfer models of good practice from one country to the other, not only because of the different healthcare systems themselves, but also because of different developments in health-related civil society organizations and in support systems for patients and/or SHGs.

The self-help support system in Germany is rather unique. No other country in the world provides such manifold professional support for patients and SHGs at regional levels. Three hundred clearinghouses and -offices for self-help are serving for around 100,000 SHGs, and several hundred further community-based information centers provide information and counseling for citizens and patients in consumer protection, care, legal affairs and patients' rights, etc. However, as research on self-help and patient involvement and the debates in these areas are usually held, written and published in German language, the German situation remains widely unknown in other countries except the German speaking like Austria or parts of Switzerland.

The characteristics of the German healthcare system with its integrated self-help support system have certainly promoted patient involvement and participation. The German Network "Self-help Friendliness and Patient Centeredness in the Healthcare System", initiated by stakeholders from all relevant healthcare areas, was an important and necessary measure for the development of systematic cooperation between healthcare providers and SHGs at the mesolevel [48].

The SHF-concept may possibly sound rather specific and seems strongly being influenced by the German legislations and circumstances. Nevertheless, there are some similarities with other approaches in other countries aiming at patient centeredness, at least concerning the individual (patient) level of patient centeredness rather than the collective (SHG) level. A study by Luxford et al. [35], for example, has recently investigated organizational barriers and facilitators towards patient-centered care in eight healthcare institutions in the USA. They conducted 40 qualitative interviews with healthcare professionals and stakeholders and shaped out nine key facilitators very similar to the quality criteria for SHF. Methods and measures may be different, but it seems obvious that change management towards patient participation, patient centeredness, public involvement or SHF needs participative approaches integrating patients and patient representatives—or specifically: self-help representatives—if a satisfactory cooperation between patients and professional healthcare staff is to be achieved. The German examples demonstrate that self-help and patient groups play an important role in further development of partnerships between patients and healthcare professionals and thus for improvements in the quality of healthcare services.

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