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Self-help friendliness and cooperation with self-help groups among rehabilitation clinics in Germany (KoReS): a mixed methods study protocol

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Self-help friendliness and cooperation with self-help groups among rehabilitation clinics in Germany (KoReS): a mixed methods study protocol

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Keywords

mixed methods, study protocol, rehabilitation, peer support, mutual aid, self-help groups, cooperation, patient orientation, comprehensive care, self-help friendliness

ABSTRACT

Introduction: Mutual aid in self-help groups is an important complement to medical rehabilitation for people with chronic diseases and disabilities. It contributes to stabilising rehabilitation success and further coping with disease and disability. Rehabilitation facilities play a central role in informing and referring patients to self-help groups. However, sustainable cooperation between rehabilitation and self-help, as can be achieved using the concept of self-help friendliness in health care, is rare, and data on the cooperation situation is lacking.

Methods and analysis: The KoReS study will examine self-help friendliness and cooperation between rehabilitation clinics and self-help associations in Germany, applying a sequential exploratory mixed methods design. In the first qualitative phase, problem-centred interviews and focus groups are conducted with representatives of self-help-friendly rehabilitation clinics, members of their cooperating self-help groups and staff of the self-help clearinghouses involved based on a purposeful sampling strategy. The qualitative data collected will be analysed through content analysis utilising MAXQDA. The findings will serve for the development of a questionnaire for a quantitative second phase. In cross-sectional studies, staff responsible for self-help in all rehabilitation clinics nationwide, representatives of self-help groups and -organisations of the core indications, as well as staff of self-help clearinghouses will be surveyed online. Quantitative data analysis with SPSS will include uni-, bi- and multivariate analyses. In addition, a content analysis of rehabilitation clinics' websites will evaluate the visibility of self-help in their public relations.

Ethics and dissemination: The UKE Ethics Committee granted ethical approval. For results dissemination, various formats such as workshops, presentations, homepages and publications for the international scientific community, rehabilitation centres, self-help organisations and the general public in Germany will be used. For relevant stakeholders, practical guides and recommendations for

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action to implement self-help friendliness will derive from the results to strengthen patient orientation and cooperation between rehabilitation and self-help to promote the sustainability of rehabilitation processes.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The mixed-method design allows for a comprehensive analysis of the cooperation situation between rehabilitation and self-help by combining the qualitative data on in-depth insights from experts in the field with quantitative survey data to quantify the extent of cooperation and its framework conditions (triangulation)
- This study is a multicentre, multiperspective investigation across Germany
- A panel of experts from the fields of self-help, rehabilitation, patient-oriented research and public health accompanies the study
- There is potential for a self-selection bias among rehabilitation centres and self-help organisations participating in the surveys
- Patients of the rehabilitation clinics are not participating in the surveys, as the study is conducted at an organisational level, focusing on institutional collaboration

MAIN TEXT

INTRODUCTION

People with chronic diseases and disabilities face considerable needs for adjustments to cope with their illness and self-management to master everyday life with as few restrictions in their quality of life as possible.[1] To achieve these aims, several offers of medical rehabilitation and reintegration exist[2] for the more than 1 million annual applicants for medical rehabilitation in Germany.[3] The majority of medical rehabilitation throughout Germany is provided on an inpatient basis. Orthopaedic and rheumatic diseases are the most common rehabilitation indication areas, which account for more than a third of inpatient rehabilitation services,[3] along other prevalent indications such as cancer, addiction, psychosomatic disorders, injuries, or neurological diseases. However, rehabilitation measures usually cannot cover the entire scope of topics and issues relevant to the everyday lives of rehabilitants due to illness or disability.[4]

To close this gap, collective self-help, also known as peer support, offers an important supplement to medical rehabilitation. Self-help comprises self-help groups (SHG), self-help organisations (SHO) and self-help clearinghouses (SHC). It contributes to coping with the disease and stabilising the success of rehabilitation.[5,6] The authentic knowledge and expertise from the shared experiences of other similarly affected patients and their relatives[7] form a 'solidarity-based mutual aid'.[8] Self-help in Germany is provided by estimated 100,000 SHG and more than 1,000 SHO at national and federal levels.[9] They are supported by a professional self-help system consisting of more than 300 SHC, which operate in regional networks in social and health care and maintain additional branch offices providing professional support services across Germany.[9] The positive effects of health-related self-help are manifold and have been demonstrated in numerous studies. Predominantly, they relate to health and psychosocial outcomes, as self-help provides psychosocial and emotional relief, for instance.[10,11] Moreover, self-help has been shown to foster empowerment[12,13] and health literacy,[14] i.e. health-related knowledge,[12,15] self-management and self-efficacy[13,16,17] of people with health related or social problems. It can further alleviate disease-related symptoms and promote healing processes through developing and maintaining healthy behaviours.[18,19]

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In order to participate in self-help activities, knowledge about self-help and referral to SHG is essential. Rehabilitation facilities are of central importance to enable this by providing information about self-help to their patients.[20] After diagnosis and acute treatment, the phase of rehabilitation is an appropriate time to draw attention to self-help, as it marks a time of convalescence in which patients recover physically and emotionally, and address the coping needs that now arise.[21] As rehabilitation usually lasts several weeks, it opens up further possibilities to systematically inform about the various options for coping with the disease or disability and stabilising the success of rehabilitation in the long term. Thus, it represents the 'initial spark',[21 (p.131)] especially as the rehabilitation goals are generally not completed in the rehabilitation service itself.[22,23]

A prerequisite for successful information and referral to self-help from rehabilitation facilities is reliable and sustainable cooperation. To achieve this, efforts have been made over the last two decades [24] and have led to some positive developments.[25-27] One measure of particular relevance is the concept of self-help friendliness (SHF) in health care and its quality criteria to establish and maintain systematic cooperation.[26,28,29] It was initiated in 2004 within a consensus process of stakeholders in the German self-help system and representatives of various health care institutions to develop, evaluate and implement quality criteria for systematic, reliable and sustainable collaboration between health care institutions and patient groups.[26,28,29] The SHF concept describes how cooperation between SHG, SHC and healthcare facilities can be structured, systematically designed and permanently implemented in practice.[26] Verifiable quality criteria were developed to assess the implementation and degree of SHF in healthcare facilities.[26] Some of these indicators of SHF have been implemented in quality management systems in healthcare facilities, however not sufficiently.[30] Consequently, to systematically promote, implement and disseminate the SHF concept, the nationwide network 'Self-Help Friendliness and Patient Orientation in Health Care' (SPiG) was founded in 2009.[30,31] The SPiG network consists of over 450 active members, including 40 rehabilitation clinics. It awards healthcare facilities that have successfully implemented the SHF quality criteria with the Self-help Friendliness quality seal, which is valid for three years. To date, 19 rehabilitation clinics and 28 hospitals have been awarded this quality seal, in some cases up to five times.[31]

Yet, despite these developments and increased positive attitudes of rehabilitation facilities towards self-help,[27] the concept is not widely used. Overall cooperation, including information about self-help and referral to SHG in the rehabilitation process, remains low.[32-34] Currently, there is a lack of data on the frequency, design and extent of cooperation between German self-help and rehabilitation facilities. Furthermore, it seems necessary to identify framework conditions and factors that facilitate and hinder cooperation in this context. Recommendations for action, such as guidelines, can then be derived from this, also to be considered for modifying existing QM systems.

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Study aims and objectives

Against this backdrop, the joint project of the Institute for Medical Sociology (IMS) at the University Medical Center Hamburg-Eppendorf (UKE) and the SPiG network investigates the cooperation between rehabilitation clinics and self-help nationwide. The project funded by the German Pension Insurance Federation examines the framework conditions and factors that aid or hinder this cooperation, with particular focus on the concept of SHF and its quality criteria. The aim is to anchor the cooperation between rehabilitation clinics and SHO and SHG more firmly in a patient-oriented manner to ensure the sustainability of rehabilitation measures through recommendations for action and implementation of SHF and its corresponding quality criteria.

The first subproject of the study explores the status and development potential of SHF at the member rehabilitation clinics of the SPiG network. Subproject two focuses on frequency, intensity and models

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of good practice regarding cooperation with self-help in rehabilitation clinics overall. The following questions are to be answered as part of the two subprojects:

Subproject 1

1. Which experience-based factors and preconditions contribute to self-help-friendly cooperation between rehabilitation clinics and self-help, what are possible obstacles?
2. From the perspective of rehabilitation clinics and self-help, how well can the SHF criteria be implemented in rehabilitation clinics, and how can cooperation with self-help be systematised and maintained?
3. What has been the experience of staff of SHC involved in cooperation to implement SHF in rehabilitation clinics?

Subproject 2

1. To what extent do cooperations between SHG and rehabilitation clinics exist, how can they be described, and which models can be distinguished?
2. Which facilitating and hindering factors for good cooperation are reported?
3. How disposed are rehabilitation clinics to implement measures for a systematic cooperation with SHG, or specifically to implement the concept of SHF, and how can this be increased?
4. What are the needs for adjustments in the QM systems relevant to rehabilitation clinics?

METHODS

Study design

The KoReS study follows an exploratory sequential mixed methods design, including qualitative and quantitative research consecutively.[35,36] It consists of two study subprojects, with a total of ten core research steps and three workshops (see Figure 1). The project is scheduled to run from August 2023 (beginning with the planning phase) to December 2025 (concluding with the writing of guides and reports), with preliminary qualitative data collection commencing in November 2023 and survey data collection starting in July 2024.

[**Figure 1** Research flow
Abbreviations: WS Workshop, SHG Self-Help Groups, SHO Self-Help Organisations, SHC Self-Help Clearinghouses]

Patient and public involvement

Patient and public involvement is an integral part of both subprojects. Representatives of self-help associations are part of the project team. In addition, a scientific advisory board and a consortium of relevant umbrella organisations accompany the study process. The scientific advisory board consists of patient representatives and experts from the fields of self-help, rehabilitation, chronic care, patient-oriented research and public health in Germany, Austria and Switzerland. Supporting organisations consist of federal working groups for self-help and rehabilitation, welfare associations, QM representatives of rehabilitation clinics, spokespersons of SHG, representatives of SHO, members of the SPiG network, and staff of SHC. They are and will be involved in the project conceptualisation, instrument development, revision of interview guides and questionnaires and overall project realisation, aiding in public relations work and recruitment of study participants. The mentioned

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stakeholders will advise on the research process and procedures as well as the interpretation of the results, contributing to how the outcomes can be used in practice, in line with the participation stages in health research.[37] Moreover, the perspectives and insights of patient representatives obtained through the qualitative interviews will directly be incorporated into this study for the quantitative phase. Three workshops will be held with all stakeholders at the beginning, middle and end of the project to foster the collaboration and dissemination of results.

Qualitative research

The qualitative research phase marks the beginning of subproject 1 to explore the cooperation status and potential between 8 out of the 40 rehabilitation clinics that are members of the SPiG network and corresponding self-help facilities through in-depth interviews and focus groups.

Sample and data collection

Semi-structured guideline-based interviews and focus groups with 8-16 representatives of 8 self-help friendly rehabilitation clinics, 8-24 members of cooperating SHG and 6-8 employees of the regional self-help clearinghouses will be conducted by the researchers based on a purposeful sampling.[38] Sampling criteria are different indication groups (cancer, neurological, orthopaedic, psychosomatic diseases, rheumatism and addiction), experience and membership duration in the network (quality seal award status), and the regional distribution of the rehabilitation clinics across different federal states. Participants from the rehabilitation clinics are employees responsible for cooperation with self-help (QM officers, social services and (other) contact persons for self-help). In addition, the experiences of the cooperating SHG or SHO and the employees of SHC responsible for SHF will be surveyed. If more than three protagonists from the self-help associations are involved in the cooperation with the respective rehabilitation clinic, focus groups will be conducted instead of individual interviews. The interview partners are recruited via gatekeeper access through the SPiG network by phone and e-mail, passing on the project description and interview topics with the participation request.

After participants' consent, the interviews and optional focus groups will be conducted via online video systems or, alternatively, by phone. The interviews will be audio-recorded and supplemented by handwritten transcripts. Volunteer spokespersons and leaders of SHG will receive an incentive of 30€ for their participation. The guidelines for the semi-structured expert interviews are developed using the SPSS method (collect, check, sort and subsume)[39] in consultation with all cooperation partners and the scientific advisory board. The interview topics were specified with the participants in the first workshop. They contain introductory questions, open narrative prompts, questions to maintain the conversation and concrete follow-up questions on four core topics (see supplement for exemplary guide): origin and development of the cooperation, cooperation design and organisation, evaluation and assessment of the cooperation, as well as cooperation needs.

The interview aim is to trace the processes in the development of cooperation and to identify the favourable and obstructive factors along the way. In addition, it will be investigated whether, how and under what conditions cooperation with self-help (and, if applicable, compliance with the SHF criteria) is implemented and actually practised. In particular, motives, expectations, needs and experiences of both rehabilitation clinics and self-help associations will be focussed on.

Data analysis

The audio recordings of the interviews and focus groups will be anonymised and transcribed by student assistants using the transcription programme F4, following the recommendations of Kuckartz,[40] Dresing and Pehl.[41] Transcripts will be considered in full for data analysis and coded deductively

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(according to the topics of the guideline) and inductively (from the transcripts), computer-assisted with the MAXQDA software. Coding units each consist of a complete sentence, and in vivo codes will be used for naming codes. The qualitative data analysis will be carried out using thematic[42] and content analysis.[40] The results form the basis for developing a questionnaire to survey the cooperation between rehabilitation clinics, SHG/SHO and SHC. Furthermore, the results should aid improving the SHF concept to implement measures that support cooperation more effectively in other rehabilitation clinics.

Quantitative research

In the second subproject, three nationwide cross-sectional online surveys will be deployed as part of the quantitative research to examine frequency, intensity and models of cooperation among SHG and SHO, SHC and all rehabilitation clinics in Germany.

Sample and data collection

Based on the preliminary qualitative study and already existing scales about SHF, a questionnaire will be developed and piloted with the QM officers and social services of the above mentioned 40 member clinics of the SPiG network and additional 20 non-member rehabilitation clinics. The questionnaire will be finalised in the second workshop. It will be used for the online survey of QM officers and social services of all the approximately 1700 inpatient, partially inpatient and outpatient rehabilitation clinics in Germany listed in the current database of Vidal MMI Germany GmbH[43] and approximately 600 representatives of the SHG and SHO corresponding to the main indications of the rehabilitation clinics. Based on previous studies, we expect at least 100 SHG and 20 SHO of each of the five core indications to participate. The estimated response rate of 20-30% regarding clinic participation draws on previous studies but is also depending on the relevant contact person in the clinics.[44-46] In parallel to the clinic survey, staff of the 105 SHC who are members of the SPiG network will be surveyed online about their experiences with SHF, with an estimated participation rate of 80%. The questionnaire to be developed for this purpose will adapt questions from the questionnaire for the rehabilitation clinics to the perspective of self-help facilities. Letters of recommendation from the relevant umbrella organisations and cooperation partners are attached to the participation call via post and e-mail, and the project will be advertised via various channels as described above to increase participation rates. Rehabilitation clinics that have not participated within two months will be sent a reminder.

The online surveys are conducted with Lime Survey to ensure data collection in compliance with data protection regulations. Participants receive an access link to the respective online questionnaire, study information and a consent and data protection declaration. After clicking on the consent button, the online questionnaire opens. Only cookies that allow the survey to continue are permitted. No IP addresses or personal data of the participants will be collected. Participation is voluntary and based on the professional function. Names and location details will be anonymised before analysis and publications. The surveys contain predominantly closed questions and free text fields on the four core topics of cooperation described above, and questions about the characteristics of the facilities. An adapted version[47] of the psychometrically tested and validated SelP-K questionnaire for measuring self-help and patient orientation in hospitals[48] will be used to assess the implementation and degree of SHF.

Data analysis

The online survey software provides the survey data in downloadable database formats. Manual data entry is thus not needed. Student assistants will perform post-coding, categorisation, and anonymisation for free text responses. Research assistants will use syntax to perform variable encoding, scale and index building, and imputations. Univariate descriptive statistics (distributions,

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means, mode, median, SD, analysis of variance), bivariate analyses (correlation, t-test, Chi²-test) and possibly multivariate statistics (logistic and linear regression) will be executed using IBM SPSS Statistics 27 or higher to compare subgroups by structural characteristics of the facilities and to identify associations for high or low levels of cooperation and SHF implementation. Statistical significance will be set at an alpha level of 0.05 for all analyses.

Website content analysis

In addition, a website content analysis of a random sample of one-fourth of all rehabilitation clinics (N ≈ 425), stratified by indications, will be conducted. Inclusion criteria are rehabilitation clinics in Germany with relevant indications and a corresponding available homepage. The websites will be screened for self-help references to quantify and evaluate the relevance of self-help in the public relations work of the facilities. For this purpose, a codebook with criteria for categorising self-help visibility will be developed to code the sample of webpages retrieved via Google. Relevant criteria include whether the website contains the word or synonyms of self-help, whether references to SHC, SHG and SHO are present, whether contact persons for self-help or a representative are available and if links to webpages of self-help exist, among others. The websites will be coded accordingly in SPSS or Excel concerning the fulfilment of the criteria, and an aggregated SHF-Index will be built to rate the visibility of self-help. Data analysis will comprise frequency counts and calculating means. A student assistant will conduct the analysis with guidance and support from a senior researcher.

Data triangulation

Both qualitative and quantitative data obtained from this project are considered as offering complementary information[49] on the subject of cooperation between rehabilitation and self-help facilities. The data will be collected sequentially and analysed separately in the initial stage. Thus, the first phase of qualitative data collection and analysis serves to explore cooperation between self-help and rehabilitation facilities from the perspectives and experiences of their responsible staff. These findings will inform the subsequent quantitative phase to develop an instrument for the quantitative survey of self-help and rehabilitation representatives. The process of integrating findings from the mixed methods will also take place at the interpretation stage after all data has been collected and analysed separately through triangulation[49] to gain a more comprehensive understanding of the facilitating and hindering factors, developments and needs concerning cooperation using these two different approaches.

ETHICS AND DISSEMINATION

Ethical considerations

Ethical approval for the study was granted by the Local Psychological Ethics Committee at the Centre for Psychosocial Medicine of the University Medical Centre Hamburg-Eppendorf (reference number LPEK-0648). A data protection concept was developed for the project to ensure adherence to relevant national and international data protection regulations for all data. It has been reviewed and approved by the data protection officers of the German Pension Insurance Federation. As part of the research project, only personal data relating to the respective institution, the job title of the respondents and their function in the rehabilitation institutions or self-help associations is collected. No specific personal data containing private information of the participants is collected. The personal data provided will be anonymised for analyses. Scientific publications will also only be made in anonymised form, unless the participants explicitly request to be named, for instance with regard to examples of good practice. Confidentiality will be maintained at all levels of data management and research data

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will be processed in accordance with applicable data protection regulations. Study data will be stored password-protected at the IMS for ten years and is only accessible to the research team. In accordance with national requirements and the principles of the Declaration of Helsinki, informed consent will be obtained from all participants prior to participation in the study. It contains information on the study objectives, scientific significance, duration, possible remuneration, the voluntary and anonymous nature of participation, information on data protection and the possibility to withdraw or terminate participation in the study at any time without adverse consequences. There are no specific risks for the participants. Participants have a contact person and only adults capable of giving consent can participate. The qualitative interviews and additional focus groups will be conducted solely by trained researchers, and interview guides and questionnaires will be pre-tested to minimise any possible psychological burden for the participants. The study has been (pre-)registered at Open Science Framework (OSF) (registration DOI https://doi.org/10.17605/OSF.IO/R9UQK).

Dissemination plan

Several dissemination channels will be considered, addressing the scientific community as well as rehabilitation stakeholders, self-help organisations, and the general public in Germany. Project progress and results will be presented and developed in participatory workshops and national conferences, and further reporting culture will be promoted through the project homepage, created for visibility and dissemination. In addition, the SPiG network and the supporting organisations will provide up-to-date information about the project progress on their homepages, newsletters and events. Publications in scientific peer-reviewed journals are planned for the international scientific community. Practical aids and recommendations for action to implement self-help friendliness for the relevant actors will derive from the results to systematically establish cooperation between self-help representatives and rehabilitation clinics, provide people with chronic illnesses and disabilities with self-help services, stabilise rehabilitation successes and foster coping and self-management. A final report on the results will also be prepared for the funder.

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Contributors

CK planned and leads the project. EZ supervises the study. EZ, IK, SB and AT contributed to the planning of the study. CK, EZ, IK, AT, TB, NU and SB are involved in executing the study. EZ outlined and wrote the manuscript. CK revised sections of the manuscript critically. AT provided guidance for the study and advice for the manuscript. TB assisted in preparing references and figures for the manuscript and public relations material. All authors approved the final manuscript.

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Competing interests

The authors declare no conflicts of interest.

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Patient and public involvement

Patients and/or the public will be involved in the design of interview guides and survey instruments, reporting, and dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication

Not applicable.

Ethics approval

Ethics approval was obtained from the Local Psychological Ethics Committee at the Center for Psychosocial Medicine, University Medical Center Hamburg (approval number LPEK-0648).

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Figure 2 Research flow
Abbreviations: WS Workshop, SHG Self-Help Groups, SHO Self-Help Organisations, SHC Self-Help Clearinghouses

Supplementary information

Interview guide for rehabilitation clinics

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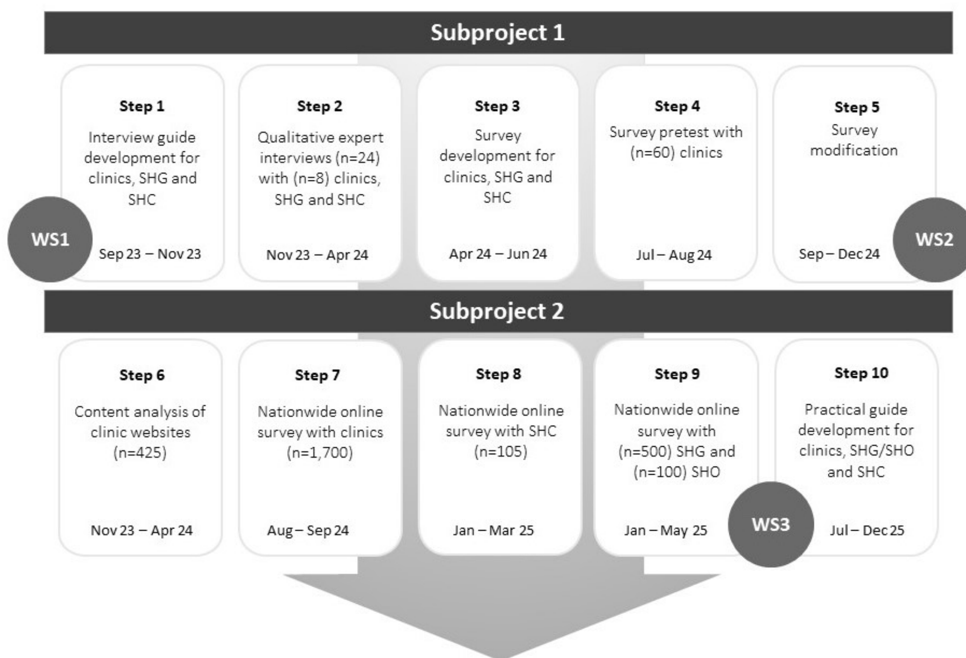

Figure 1 Research flow
Abbreviations: WS Workshop, SHG Self-Help Groups, SHO Self-Help Organisations, SHC Self-Help Clearinghouses

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SUPPLEMENTARY INFORMATION

Interview guide for rehabilitation clinics

a) Introduction/Introductory questions

- Thanks for agreement to participate
- Brief summary of the project/goals/team
- Importance of the interview for the exploration of the cooperation process and the development of a standardised questionnaire
- Goal: Exchange of experiences regarding cooperation work, there is no right/wrong (experiences, wishes, needs)
- Consent to audio recording / recording of interview
- Anonymity or visibility in reports desired? Assure confidentiality
- Introduction: How long have you been active as self-help representative/contact person in the rehabilitation clinic? Was there a self-help representative before your employment in this position?
- Would you please briefly describe your responsibilities? Do you receive additional compensation or other benefits for this position?
- Which patients do you usually deal with (briefly)?

b) Questions about the importance of SH

- In your opinion as representative in a rehabilitation clinic, what is the importance of self-help for patients in rehabilitation clinics?

c) Main part/questions on cooperation

1. Development of cooperation

- Which self-help actors (SHG/SHO/SHC) are you in contact with?
- Could you describe how your cooperation with the self-help actors (SHG/SHO/SHC) we are interviewing as well came about?
  Since when? Who took the initiative/established contact? With what goal/expectations/motivation), On what basis? (Framework conditions: legal requirements, guidelines, provider structures), To what extent?

2. Organisation of Cooperation

- In what form does your rehabilitation clinic cooperate with these self-help actors and, if applicable, a SHC?
- What are the main goals of the cooperation?
- What self-help services do you offer at the rehabilitation clinic? Who offers them? Where do the services take place? Who exactly are the services aimed at? How are they accepted?
- With regard to the cooperation between SH and rehabilitation clinics, the concept of self-help friendliness (SHF) is a central topic. The concept contains five quality criteria for SHF. Do you know these criteria and are they implemented in your rehabilitation clinic?

  Name five quality criteria for SHF. Please indicate to what extent the statements apply to your cooperating rehabilitation clinic.
  - If you had to make a spontaneous assessment, to what extent is criteria x implemented?
  - By whom and with which measures is criteria x implemented?

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- Which (supportive and obstructive) factors play a role in the implementation of the criteria? (after asking about the five criteria)
- Are the measures for implementing the criteria regularly discussed in a quality circle or team meeting?
- Do you find the five criteria sufficient? If you had a free choice and could add criteria, which ones would you add?

Implementation of the cooperation, SHF quality criteria (additional: public relations intensity, website information, display of information material, provision of rooms, exchange of experiences, participation in quality circles, further training opportunities, participation), importance of the cooperation, integration into QM (what, how, where, when, how often, with whom, by whom)

- Are patients referred to SHG by your rehabilitation clinic? If yes, through which access routes?
- How could the motivation of rehabilitation patients to join an SHG be increased? What influence do they have?
  - Certain actors from the self-help and rehabilitation sector (e.g. self-help representatives of the rehabilitation clinic, local self-help clearinghouses, SPiG network)
  - Framework conditions (in particular contracts/agreements) on the success of cooperation with the rehabilitation clinic?

Health policy guidelines by federal/state ministries, organisational structures, contracts, role/responsibilities of SH and rehabilitation providers/associations, sponsors, certification pressure) Resources (personnel: Are there SHRs? Activities, areas of responsibility, time, space, financial), systems (guidelines for action, QM integration, etc.), digital services

3. Evaluation/Assessment of the Cooperation process

- How would you rate the overall quality of the cooperation (school grades)? *In addition: Regular evaluations, effectiveness (successful mediation, acceptance, motivation, actual use), importance for rehabilitants + subjective benefits, sustainability of cooperation, digital offers*

4. Needs

- What would you like to see to improve cooperation with rehabilitation clinics and SHC?
- Do you have any wishes regarding your cooperation with certain actors in the self-help, rehabilitation or health care sectors as a whole and in particular with the SPiG network?

Structures/framework conditions, resources (personnel/time/space, acquisitions), SHG presence + offer, external presentation of the SHR, plans and wishes (own and rehabilitation clinics + possibly SHC, e.g. financial compensation etc.), communication between the actors, digital offers, outlook

d) Final questions and information

- Is there anything else you would like to tell me about your work as a representative?
- Are there any relevant points that remained open during the interview?
- Information about the project and ways to contact us
- Reference to homepage and next steps (evaluation, results for the questionnaire)
- Thanks

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Self-help friendliness and cooperation with self-help groups among rehabilitation clinics in Germany (KoReS): a mixed-methods study protocol

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Self-help friendliness and cooperation with self-help groups among rehabilitation clinics in Germany (KoReS): a mixed-methods study protocol

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Keywords

mixed methods, study protocol, rehabilitation, peer support, mutual aid, self-help groups, cooperation, patient orientation, comprehensive care, self-help friendliness

ABSTRACT

Introduction: Self-help is an important complement to medical rehabilitation for people with chronic diseases and disabilities. It contributes to stabilising rehabilitation success and further coping with disease and disability. Rehabilitation facilities are central in informing and referring patients to self-help groups. However, sustainable cooperation between rehabilitation and self-help, as can be achieved using the concept of self-help friendliness in health care, is rare, as is data on the cooperation situation.

Methods and analysis: The KoReS study will examine self-help friendliness and cooperation between rehabilitation clinics and self-help associations in Germany, applying a sequential exploratory mixed-methods design. In the first qualitative phase, problem-centred interviews and focus groups are conducted with representatives of self-help-friendly rehabilitation clinics, members of their cooperating self-help groups and staff of self-help clearinghouses involved based on a purposeful sampling. Qualitative data collected will be analysed through content analysis utilising MAXQDA. The findings will serve to develop a questionnaire for a quantitative second phase. Cross-sectional online studies will survey staff responsible for self-help in rehabilitation clinics nationwide, representatives of self-help groups, and staff of self-help clearinghouses. Quantitative data analysis with SPSS will include descriptive statistics, correlation, subgroup and multiple regression analyses. Additionally, a content analysis of rehabilitation clinics' websites will evaluate the visibility of self-help in their public relations.

Ethics and dissemination: The UKE Local Psychological Ethics Committee at the Centre for Psychosocial Medicine granted ethical approval (reference number LPEK-0648; 10.07.2023). Informed consent will be obtained from all participants. Results dissemination will comprise various formats such as workshops, presentations, homepages and publications for the international scientific community,

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rehabilitation centres, self-help organisations and the general public in Germany. For relevant stakeholders, practical guides and recommendations to implement self-help friendliness will derive from the results to strengthen patient orientation and cooperation between rehabilitation and self-help to promote the sustainability of rehabilitation processes.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The mixed-methods design allows for a comprehensive analysis of the cooperation situation between rehabilitation and self-help by combining the qualitative data on in-depth insights from experts in the field with quantitative survey data to quantify the extent of cooperation and its framework conditions (triangulation).
- This study is a multicentre, multi-perspective investigation being conducted across Germany.
- A panel of experts from the fields of self-help, rehabilitation, patient-oriented research and public health accompanies the study by advising on methodology and instrument development and supporting participant recruitment as well as public relations.
- There is potential for a self-selection bias among rehabilitation centres and self-help organisations participating in the surveys.
- Patients of the rehabilitation clinics are not participating in the surveys, as the study is conducted at an organisational level, focusing on institutional collaboration.

INTRODUCTION

People with chronic diseases and disabilities face considerable needs for adjustments to cope with their illness and self-management to master everyday life with as few restrictions in their quality of life as possible.[1] To achieve these aims, several offers of medical rehabilitation and reintegration exist for the more than 1 million annual applicants for medical rehabilitation in Germany.[2,3] Medical rehabilitation in Germany includes follow-up (aftercare) rehabilitation taking place immediately after a hospital stay, indication-specific rehabilitation tailored to a particular illness such as cancer, addiction or musculoskeletal disorders, geriatric rehabilitation for older patients with multiple health issues and additionally, target group-specific rehabilitation for specific groups such as children, adolescents, parents, or carers.[3] Medical rehabilitation throughout Germany is mainly provided on an inpatient basis, but can also take place on an outpatient basis. Orthopaedic and rheumatic diseases are the most common rehabilitation indication areas, which account for more than a third of inpatient rehabilitation services,[3] along other prevalent indications such as cancer, addiction, psychosomatic disorders, injuries, or neurological diseases. However, rehabilitation measures usually cannot cover the entire scope of topics and issues relevant to the everyday lives of rehabilitants due to illness or disability.[4]

To close this gap, collective self-help, also known as peer support, offers an important supplement to medical rehabilitation. Self-help comprises self-help groups (SHG), self-help organisations (SHO) and self-help clearinghouses (SHC). It contributes to coping with the disease and stabilising the success of rehabilitation.[5,6] The authentic knowledge and expertise from the shared experiences of other similarly affected patients and their relatives[7] form a 'solidarity-based mutual aid'.[8] Self-help in Germany is provided by estimated 100,000 SHG and more than 1,000 SHO at national and federal levels.[9] They are supported by a professional self-help system consisting of more than 300 SHC, which operate in regional networks in social and health care and maintain additional branch offices providing professional support services across Germany.[9] The SHC in Germany are working as central contact points for regional SHG and anyone interested in information on self-help. The main tasks of SHC

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include advising and referring interested parties to SHG, assistance in setting up new SHG, technical and organisational support for existing SHG, public relations work for self-help and existing SHG, and networking and cooperating with other support organisations in the social and healthcare sector.[8,9] The positive effects of health-related self-help are manifold and have been demonstrated in numerous studies. Predominantly, they relate to health and psychosocial outcomes, as self-help provides psychosocial and emotional relief, for instance.[10,11] Moreover, self-help has been shown to foster empowerment[12,13] and health literacy,[14] i.e. health-related knowledge,[12,15] self-management and self-efficacy[13,16,17] of people with health related or social problems. It can further alleviate disease-related symptoms and promote healing processes through developing and maintaining healthy behaviours.[18,19]

In order to participate in self-help activities, knowledge about self-help and referral to SHG is essential. Rehabilitation facilities are of central importance to enable this by providing information about self-help to their patients.[20] After diagnosis and acute treatment, the phase of rehabilitation is an appropriate time to draw attention to self-help, as it marks a time of convalescence in which patients recover physically and emotionally, and address the coping needs that now arise.[21] As rehabilitation usually lasts several weeks, it opens up further possibilities to systematically inform about the various options for coping with the disease or disability and stabilising the success of rehabilitation in the long term. Thus, it represents the 'initial spark',[21 p. 131] especially as the rehabilitation goals are generally not completed in the rehabilitation service itself.[22,23]

A prerequisite for successful information and referral to self-help from rehabilitation facilities is reliable and sustainable cooperation. To achieve this, efforts have been made over the last two decades [24] and have led to some positive developments.[25-27] One measure of particular relevance is the concept of self-help friendliness (SHF) in health care and its quality criteria to establish and maintain systematic cooperation.[26,28,29] It was initiated in 2004 within a consensus process of stakeholders in the German self-help system and representatives of various health care institutions to develop, evaluate and implement quality criteria for systematic, reliable and sustainable collaboration between health care institutions and patient groups.[26,28,29] The SHF concept describes how cooperation between SHG, SHC and healthcare facilities can be structured, systematically designed and permanently implemented in practice.[26] Verifiable quality criteria (see **supplementary file 1** for quality criteria for rehabilitation clinics) were developed to assess the implementation and degree of SHF in healthcare facilities.[26] Some of these indicators of SHF have been implemented in quality management systems in healthcare facilities, however not sufficiently.[30] Consequently, to systematically promote, implement and disseminate the SHF concept, the nationwide network 'Self-Help Friendliness and Patient Orientation in Health Care' (SPiG) was founded in 2009.[30,31] The SPiG network consists of over 450 active members, including 40 rehabilitation clinics. It awards healthcare facilities that have successfully implemented the SHF quality criteria [31] with the Self-help Friendliness quality seal, which is valid for three years. To date, 19 rehabilitation clinics and 28 hospitals have been awarded this quality seal, in some cases up to five times.[31]

Yet, despite these developments and increased positive attitudes of rehabilitation facilities towards self-help,[27] the concept is not widely used. Overall cooperation, including information about self-help and referral to SHG in the rehabilitation process, remains low.[32-34] Currently, there is a lack of data on the frequency, design and extent of cooperation between German self-help and rehabilitation facilities. Furthermore, it seems necessary to identify framework conditions (e.g. legal requirements, regulations, contracts, regional structures) and factors that facilitate and hinder cooperation in this context. Recommendations for action, such as guidelines, can then be derived from this, also to be considered for modifying existing QM systems.

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Study aims and objectives

Against this backdrop, the joint project of the Institute for Medical Sociology (IMS) at the University Medical Center Hamburg-Eppendorf (UKE) and the SPiG network investigates the cooperation between rehabilitation clinics and self-help nationwide. The project funded by the German Pension Insurance Federation examines the framework conditions and factors that aid or hinder this cooperation, with particular focus on the concept of SHF and its quality criteria for rehabilitation clinics. The aim is to anchor the cooperation between rehabilitation clinics and SHO and SHG more firmly in a patient-oriented manner to ensure the sustainability of rehabilitation measures through recommendations for action and implementation of SHF and its corresponding quality criteria.

The first subproject of the study explores the status and development potential of SHF at the member rehabilitation clinics of the SPiG network. Subproject two focuses on frequency, intensity and models of good practice regarding cooperation with self-help in rehabilitation clinics overall. The following questions are to be answered as part of the two subprojects:

Subproject 1

1. Which experience-based factors and preconditions contribute to self-help-friendly cooperation between rehabilitation clinics and self-help, what are possible obstacles?
2. From the perspective of rehabilitation clinics and self-help, how well can the SHF criteria be implemented in rehabilitation clinics, and how can cooperation with self-help be systematised and maintained?
3. What has been the experience of staff of SHC involved in cooperation to implement SHF in rehabilitation clinics?

Subproject 2

1. To what extent do cooperations between SHG and rehabilitation clinics exist, how can they be described, and which models can be distinguished?
2. Which facilitating and hindering factors for good cooperation are reported?
3. How disposed are rehabilitation clinics to implement measures for a systematic cooperation with SHG, or specifically to implement the concept of SHF, and how can this be increased?
4. What are the needs for adjustments in the QM systems relevant to rehabilitation clinics?

METHODS AND ANALYSIS

Study design

The KoReS study follows an exploratory sequential mixed-methods design, including qualitative and quantitative research consecutively.[35,36] It consists of two study subprojects, with a total of ten core research steps and three workshops (see Figure 1). The project is scheduled to run from August 2023 (beginning with the planning phase) to December 2025 (concluding with the writing of guides and reports), with preliminary qualitative data collection commencing in November 2023 and survey data collection starting in July 2024.

Patient and public involvement

Patient and public involvement is an integral part of both subprojects. Representatives of self-help associations are part of the project team, having expertise in collaborating with diverse SHG of various indication groups. In addition, a scientific advisory board and a consortium of relevant umbrella organisations accompany the study process. The scientific advisory board consists of patient

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representatives and experts from the fields of self-help, rehabilitation, chronic care, patient-oriented research and public health in Germany, Austria and Switzerland. Supporting organisations consist of federal working groups for self-help and rehabilitation, welfare associations, QM representatives of rehabilitation clinics, spokespersons of SHG, representatives of SHO, members of the SPiG network, and staff of SHC. They are and will be involved in the project conceptualisation, instrument development, revision of interview guides and questionnaires and overall project realisation, aiding in public relations work and recruitment of study participants. The mentioned stakeholders will advise on the research process and procedures as well as the interpretation of the results, contributing to how the outcomes can be used in practice, in line with the participation stages in health research.[37] Moreover, the perspectives and insights of patient representatives obtained through the qualitative interviews will directly be incorporated into this study for the quantitative phase. Three workshops will be held with all stakeholders at the beginning, middle and end of the project to foster the collaboration and dissemination of results.

Qualitative research

The qualitative research phase marks the beginning of subproject 1 to explore the cooperation status and potential between 8 out of the 40 rehabilitation clinics that are members of the SPiG network and corresponding self-help facilities through in-depth interviews and focus groups. It aims to trace the processes in the development of cooperation and to identify the favourable and obstructive factors along the way. In addition, it will be investigated whether, how and under what conditions cooperation with self-help (and, if applicable, compliance with the SHF criteria) is implemented and actually practised. In particular, motives, expectations, needs and experiences of both rehabilitation clinics and self-help associations will be focussed on.

Sample and data collection

Semi-structured guideline-based interviews and focus groups with 8-16 representatives of 8 self-help friendly rehabilitation clinics, 8-24 members of cooperating SHG and 6-8 employees of the regional self-help clearinghouses will be conducted by the researchers based on a purposeful sampling.[38] Sampling criteria are to cover a broad range of different indications of the five core indication groups (oncological, neurological, orthopaedic, psychosomatic and addictive diseases or disorders), selecting member clinics with different levels of experience and varying membership duration in the network (quality seal award status), and regional distribution of the rehabilitation clinics across different federal states. Participants from the rehabilitation clinics are employees responsible for cooperation with self-help (QM officers, social services and (other) contact persons for self-help). In addition, the experiences of the cooperating SHG or SHO and the employees of SHC responsible for SHF will be surveyed. If more than three protagonists from the self-help associations are involved in the cooperation with the respective rehabilitation clinic, focus groups will be conducted instead of individual interviews. The interview partners are recruited via gatekeeper access through the SPiG network by phone and e-mail, passing on the project description and interview topics with the participation request.

After participants' consent, the interviews and optional focus groups will be conducted via online video systems, by phone or, alternatively, face-to-face. The interviews will be audio-recorded and supplemented by handwritten transcripts. Volunteer spokespersons and leaders of SHG will receive an incentive of 30€ for their participation. The guidelines for the semi-structured expert interviews are developed using the SPSS method (collect, check, sort and subsume)[39] in consultation with all cooperation partners and the scientific advisory board. The interview topics were specified with the participants in the first workshop. They contain introductory questions, open narrative prompts, questions to maintain the conversation and concrete follow-up questions on four core topics (see

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supplementary file 2 for exemplary guide): origin and development of the cooperation, cooperation design and organisation, evaluation and assessment of the cooperation, as well as cooperation needs.

Data analysis

The audio recordings of the interviews and focus groups will be anonymised and transcribed by student assistants using the transcription programme F4, following the recommendations of Kuckartz,[40] Dresing and Pehl.[41] Transcripts will be considered in full for data analysis and coded deductively (according to the topics of the guideline) and inductively (from the transcripts), computer-assisted with the MAXQDA software. Coding units each consist of a complete sentence, and in vivo codes will be used for naming codes. The qualitative data analysis will be carried out using thematic [42] and content analysis.[40] The results form the basis for developing a questionnaire to survey the cooperation between rehabilitation clinics, SHG/SHO and SHC. Furthermore, the results should aid improving the SHF concept to implement measures that support cooperation more effectively in other rehabilitation clinics.

Quantitative research

In the second subproject, three nationwide cross-sectional online surveys will be deployed as part of the quantitative research to examine frequency, intensity and models of cooperation among SHG and SHO, SHC and all rehabilitation clinics in Germany.

Sample and data collection

Based on the preliminary qualitative study and already existing scales about SHF, a questionnaire will be developed and piloted (see steps 3 and 4 of the research flow in Figure 1) with the QM officers and social services of the above mentioned 40 member clinics of the SPiG network and additional 20 non-member rehabilitation clinics. After psychometric pretesting, the questionnaire will be modified, where applicable and finalised in the second workshop (step 5). It will be used for the online survey of QM officers and social services of all the approximately 1700 inpatient, partially inpatient and outpatient rehabilitation clinics in Germany listed in the current database of Vidal MMI Germany GmbH[43] and approximately 600 representatives of the SHG and SHO corresponding to the main indications of the rehabilitation clinics. Based on previous studies, we expect at least 100 SHG and 20 SHO of each of the five core indications to participate. The estimated response rate of 20-30% regarding clinic participation draws on previous studies but is also depending on the relevant contact person in the clinics.[44-46] In parallel to the clinic survey, staff of the 105 SHC who are members of the SPiG network will be surveyed online about their experiences with SHF, with an estimated participation rate of 80% based on their membership commitment and the associated objectives and field of activity to promote SHF. To enable triangulation and multi-perspectivity, the questionnaire to be developed for this purpose will be adapted from the questionnaire for the rehabilitation clinics to the perspective of self-help facilities. Letters of recommendation from the relevant umbrella organisations and cooperation partners are attached to the participation call via post and e-mail, and the project will be advertised via various channels as described above to increase participation rates. Rehabilitation clinics that have not participated within two months will be sent a reminder.

The online surveys are conducted with Lime Survey to ensure data collection in compliance with data protection regulations. Participants receive an access link to the respective online questionnaire, study information and a consent and data protection declaration. After clicking on the consent button, the online questionnaire opens. Only cookies that allow the survey to continue are permitted. No IP addresses or personal data of the participants will be collected. Participation is voluntary and based on the professional function. Names and location details will be anonymised before analysis and publications. The surveys contain predominantly closed questions and free text fields on the four core

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3 topics of cooperation described above, and questions about the characteristics of the facilities. An adapted scale[47] of the psychometrically tested and validated SelP-K questionnaire [48] for measuring self-help and patient orientation in hospitals will be used to assess the implementation and degree of SHF, which has shown very good internal consistency (α = .90).[47]

Data analysis

The online survey software provides the survey data in downloadable database formats. Manual data entry is thus not needed. Student assistants will perform post-coding, categorisation, and anonymisation for free text responses. Research assistants will use syntax to perform variable encoding, scale and index building, and possible missing value imputations (i.e. mean value imputation). Univariate descriptive statistics (distributions, means, mode, median, SD, analysis of variance) will be used to assess frequency, intensity and models of cooperation and examine SHF implementation. Further, bivariate analyses (correlation, t-test, Chi²-test) will be conducted to compare subgroups by structural characteristics of the facilities in terms of their cooperation experiences, and possibly multivariate statistics (logistic and linear regression) will be executed to identify associations for high or low levels of cooperation, i.e. hindering and facilitating factors for cooperation. For quantitative data analysis, IBM SPSS Statistics 27 or higher will be used, and statistical significance will be set at an alpha level of 0.05.

Website content analysis

In addition, a website content analysis of a random sample of one-fourth of all rehabilitation clinics (N ≈ 425), stratified by indications, will be conducted. Inclusion criteria are rehabilitation clinics in Germany with relevant indications and a corresponding available homepage. The websites will be screened for self-help references to quantify and evaluate the relevance of self-help in the public relations work of the facilities. For this purpose, a codebook with criteria for categorising self-help visibility will be developed to code the sample of webpages retrieved via Google. Relevant criteria include whether the website contains the word or synonyms of self-help, whether references to SHC, SHG and SHO are present, whether contact persons for self-help or a representative are available and if links to webpages of self-help exist, among others. The websites will be coded accordingly in SPSS or Excel concerning the fulfilment of the criteria, and an aggregated SHF-Index will be built to rate the visibility of self-help. Data analysis will comprise frequency counts and calculating means. A student assistant will conduct the analysis with guidance and support from a senior researcher.

Data triangulation

Both qualitative and quantitative data obtained from this project are considered as offering complementary information [49] on the subject of cooperation between rehabilitation and self-help facilities. The data will be collected sequentially and analysed separately in the initial stage. Thus, the first phase of qualitative data collection and analysis serves to explore cooperation between self-help and rehabilitation facilities from the perspectives and experiences of their responsible staff. These findings will inform the subsequent quantitative phase to develop an instrument for the quantitative survey of self-help and rehabilitation representatives. The process of integrating findings from the mixed methods will also take place at the interpretation stage after all data has been collected and analysed separately through triangulation [49] to gain a more comprehensive understanding of the facilitating and hindering factors, developments and needs concerning cooperation using these two different approaches.

ETHICS AND DISSEMINATION

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Ethical considerations

Ethical approval for the study was granted by the Local Psychological Ethics Committee at the Centre for Psychosocial Medicine of the University Medical Centre Hamburg-Eppendorf (reference number LPEK-0648). A data protection concept was developed for the project to ensure adherence to relevant national and international data protection regulations for all data. It has been reviewed and approved by the data protection officers of the German Pension Insurance Federation. As part of the research project, only personal data relating to the respective institution, the job title of the respondents and their function in the rehabilitation institutions or self-help associations is collected. No specific personal data containing private information of the participants is collected. The personal data provided will be anonymised for analyses. Scientific publications will also only be made in anonymised form, unless the participants explicitly request to be named, for instance with regard to examples of good practice. Confidentiality will be maintained at all levels of data management and research data will be processed in accordance with applicable data protection regulations. Study data will be stored password-protected at the IMS for ten years and is only accessible to the research team. In accordance with national requirements and the principles of the Declaration of Helsinki, informed consent will be obtained from all participants prior to participation in the study. It contains information on the study objectives, scientific significance, duration, possible remuneration, the voluntary and anonymous nature of participation, information on data protection and the possibility to withdraw or terminate participation in the study at any time without adverse consequences. There are no specific risks for the participants. Participants have a contact person and only adults capable of giving consent can participate. The qualitative interviews and additional focus groups will be conducted solely by trained researchers, and interview guides and questionnaires will be pre-tested to minimise any possible psychological burden for the participants. The study has been (pre-)registered at Open Science Framework (OSF) (registration DOI https://doi.org/10.17605/OSF.IO/R9UQK).

Dissemination plan

Several dissemination channels will be considered, addressing the scientific community as well as rehabilitation stakeholders, self-help organisations, and the general public in Germany. Project progress and results will be presented and developed in participatory workshops and national conferences, and further reporting culture will be promoted through the project homepage, created for visibility and dissemination. In addition, the SPiG network and the supporting organisations will provide up-to-date information about the project progress on their homepages, newsletters and events. Publications in scientific peer-reviewed journals are planned for the international scientific community. Practical aids and recommendations for action to implement self-help friendliness for the relevant actors will derive from the results to systematically establish cooperation between self-help representatives and rehabilitation clinics, provide people with chronic illnesses and disabilities with self-help services, stabilise rehabilitation successes and foster coping and self-management. A final report on the results will also be prepared for the funder.

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Contributors

CK planned and leads the project. EZ supervises the study. EZ, IK, SB and AT contributed to the planning of the study. CK, EZ, IK, AT, TB, NU and SB are involved in executing the study. EZ outlined and wrote the manuscript. CK revised sections of the manuscript critically. AT provided guidance for the study and advice for the manuscript. TB assisted in preparing references and figures for the manuscript and public relations material. All authors approved the final manuscript.

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Competing interests

The authors declare no conflicts of interest.

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Patient and public involvement

Patients and/or the public will be involved in the design of interview guides and survey instruments, reporting, and dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication

Not applicable.

Ethics approval

Ethics approval was obtained from the Local Psychological Ethics Committee at the Center for Psychosocial Medicine, University Medical Center Hamburg (approval number LPEK-0648).

Provenance and peer review

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Supplemental material

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Figure 1 Research flow

Abbreviations: WS Workshop, SHG Self-Help Groups, SHO Self-Help Organisations, SHC Self-Help Clearinghouses.

Supplementary materials

Quality criteria for self-help friendly rehabilitation clinics

Interview guide for rehabilitation clinics

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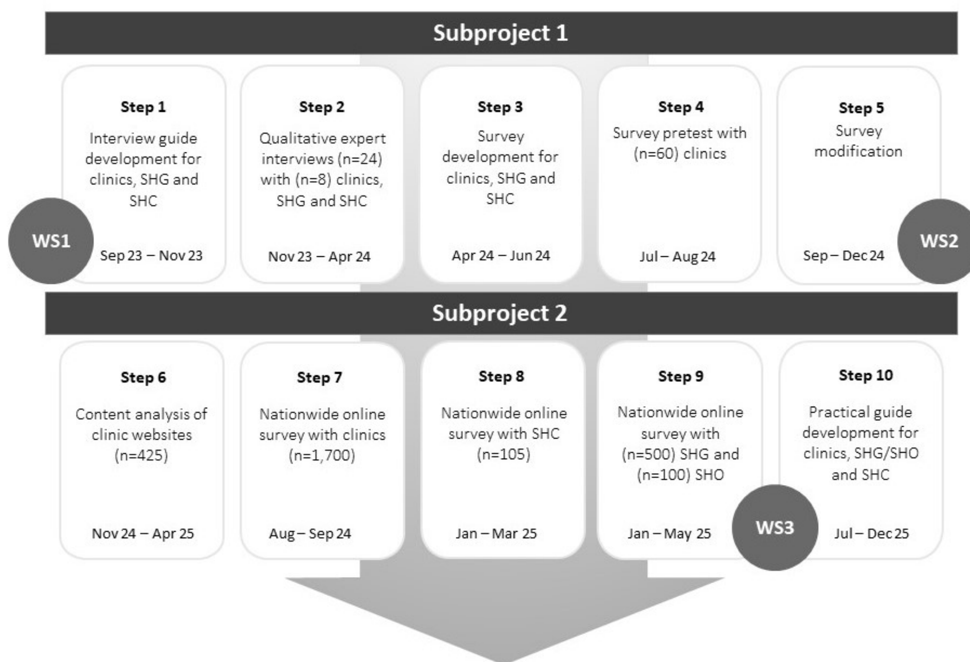

Figure 1 Research flow
Abbreviations: WS Workshop, SHG Self-Help Groups, SHO Self-Help Organisations, SHC Self-Help Clearinghouses

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SUPPLEMENTARY INFORMATION

Quality criteria for self-help friendly rehabilitation clinics

Five quality criteria for self-help friendliness have been developed through mutual agreement between clinic representatives and self-help organisations, specifically tailored to the particular needs of rehabilitation clinics and their patients. They reflect the most important aspects of self-help friendliness and provide guidance on how cooperation between rehabilitation clinics and self-help groups or organisations can be organised in concrete terms.

1. Self-presentation is made possible

The rehabilitation centre informs patients and their relatives at central locations in its facility, in its rooms and its media about the importance of self-help in rehabilitation and about its cooperation with indication-related self-help groups and organisations.

2. The possibility of participation is pointed out

During the rehabilitation programme, patients and their relatives are regularly and personally informed about the possibility of participating in a self-help group that is suitable for them.

3. A contact person is appointed

The rehabilitation facility appoints a contact person for self-help affairs and makes this person known to patients and staff.

4. Training is provided on the subject of self-help

Employees of the rehabilitation facility are informed about self-help in general and concerning the most common conditions that occur in the facility.

5. Cooperation is reliably organised

Rehabilitation facility and self-help make specific agreements on cooperation and regular exchange.

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SUPPLEMENTARY INFORMATION

Interview guide for rehabilitation clinics

a) Introduction/Introductory questions

- Thanks for agreement to participate
- Brief summary of the project/goals/team
- Importance of the interview for the exploration of the cooperation process and the development of a standardised questionnaire
- Goal: Exchange of experiences regarding cooperation work, there is no right/wrong (experiences, wishes, needs)
- Consent to audio recording / recording of interview
- Anonymity or visibility in reports desired? Assure confidentiality
- Introduction: How long have you been active as self-help representative/contact person in the rehabilitation clinic? Was there a self-help representative before your employment in this position?
- Would you please briefly describe your responsibilities? Do you receive additional compensation or other benefits for this position?
- Which patients do you usually deal with (briefly)?

b) Questions about the importance of SH

- In your opinion as representative in a rehabilitation clinic, what is the importance of self-help for patients in rehabilitation clinics?

c) Main part/questions on cooperation

1. Development of cooperation

- Which self-help actors (SHG/SHO/SHC) are you in contact with?
- Could you describe how your cooperation with the self-help actors (SHG/SHO/SHC) we are interviewing as well came about?
  Since when? Who took the initiative/established contact? With what goal/expectations/motivation), On what basis? (Framework conditions: legal requirements, guidelines, provider structures), To what extent?

2. Organisation of Cooperation

- In what form does your rehabilitation clinic cooperate with these self-help actors and, if applicable, a SHC?
- What are the main goals of the cooperation?
- What self-help services do you offer at the rehabilitation clinic? Who offers them? Where do the services take place? Who exactly are the services aimed at? How are they accepted?
- With regard to the cooperation between SH and rehabilitation clinics, the concept of self-help friendliness (SHF) is a central topic. The concept contains five quality criteria for SHF. Do you know these criteria and are they implemented in your rehabilitation clinic?

  Name five quality criteria for SHF. Please indicate to what extent the statements apply to your cooperating rehabilitation clinic.

  - If you had to make a spontaneous assessment, to what extent is criteria x implemented?
  - By whom and with which measures is criteria x implemented?

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- Which (supportive and obstructive) factors play a role in the implementation of the criteria? (after asking about the five criteria)
- Are the measures for implementing the criteria regularly discussed in a quality circle or team meeting?
- Do you find the five criteria sufficient? If you had a free choice and could add criteria, which ones would you add?

Implementation of the cooperation, SHF quality criteria (additional: public relations intensity, website information, display of information material, provision of rooms, exchange of experiences, participation in quality circles, further training opportunities, participation), importance of the cooperation, integration into QM (what, how, where, when, how often, with whom, by whom)

- Are patients referred to SHG by your rehabilitation clinic? If yes, through which access routes?
- How could the motivation of rehabilitation patients to join an SHG be increased? What influence do they have?
  - Certain actors from the self-help and rehabilitation sector (e.g. self-help representatives of the rehabilitation clinic, local self-help clearinghouses, SPiG network)
  - Framework conditions (in particular contracts/agreements) on the success of cooperation with the rehabilitation clinic?

Health policy guidelines by federal/state ministries, organisational structures, contracts, role/responsibilities of SH and rehabilitation providers/associations, sponsors, certification pressure) Resources (personnel: Are there SHRs? Activities, areas of responsibility, time, space, financial), systems (guidelines for action, QM integration, etc.), digital services

3. Evaluation/Assessment of the Cooperation process

- How would you rate the overall quality of the cooperation (school grades)? *In addition: Regular evaluations, effectiveness (successful mediation, acceptance, motivation, actual use), importance for rehabilitants + subjective benefits, sustainability of cooperation, digital offers*

4. Needs

- What would you like to see to improve cooperation with rehabilitation clinics and SHC?
- Do you have any wishes regarding your cooperation with certain actors in the self-help, rehabilitation or health care sectors as a whole and in particular with the SPiG network?

Structures/framework conditions, resources (personnel/time/space, acquisitions), SHG presence + offer, external presentation of the SHR, plans and wishes (own and rehabilitation clinics + possibly SHC, e.g. financial compensation etc.), communication between the actors, digital offers, outlook

d) Final questions and information

- Is there anything else you would like to tell me about your work as a representative?
- Are there any relevant points that remained open during the interview?
- Information about the project and ways to contact us
- Reference to homepage and next steps (evaluation, results for the questionnaire)
- Thanks

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