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Cancer peer support – association with patients' empowerment and integration in oncological care

Dissertation

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Table of contents

1. Synopsis

Overall, this dissertation aims to provide quantitative evidence to gain insight into the association between empowerment dimensions and cancer peer support participation. Zooming into knowledge as one central element of empowerment, it aims to make patients' cancer-specific knowledge measurable, to collect it nationwide among German patients within and outside of a peer support group (PSG) to explore their possible differences and the association of peer support and empowerment further. Finally, it serves to examine the state of integration of cancer peer support in routine cancer care through quantitative research given the lack of data on this despite growing efforts of integration. This research follows a sequential mixed-methods design and includes participatory research with relevant stakeholders of the field. The findings serve to identify the role of cancer peer support for empowerment in the context of oncology care and can impact and improve comprehensive patient-centred, integrated cancer care.

Since research which systematically gathers quantitative evidence on the association of participation in cancer peer support on empowerment is scarce, a systematic review was conducted first. Secondly, a practicable knowledge scale was developed as knowledge is a key element of peer support and empowerment, but current measures have proven unsuitable for objectively assessing multidimensional cancer knowledge for cancer patients across different cancer entities and healthcare contexts. Subsequently, the scale was tested in a survey among cancer patients consisting of members and non-members of PSGs in Germany, to assess the association of peer support with knowledge as an empowerment dimension. Lastly, considering that cancer peer support seems to pose a critical element of empowerment resources for cancer patients, its integration into cancer care is examined through a survey with leaders of cancer PSGs, as the first of its kind.

Therefore, the initial chapter of this work provides contextual background information on peer support in German cancer care and the theoretical basis of psychological empowerment (PE) and presents possible measures of PE and its three components. It discusses current evidence on the subject, its relevance and research gaps, focusing on knowledge as the central element of the interactional component of PE. Next, the aims of this dissertation are described and the methods and materials used to carry out the studies are outlined. This is followed by a summary of the main research findings of the conducted studies. Following a discussion of the findings of this thesis in light of other research, this chapter concludes by elaborating on possible implications and perspectives for practice derived from the results as well as on the strengths and weaknesses of the conducted studies.

1.1. Background

The following chapter focuses on the relevance of peer support in the setting of cancer care embedded in the theoretical concept of empowerment, highlights the current state of research and presents the goals and objectives of this thesis.

1.1.1. Peer support in cancer care

Cancer in Germany

Cancer lethality has decreased over the past years, while cancer incidence rates continue to rise globally.[1] In 2020, there were an estimated 19 million new cancer cases and nearly 10 million cancer deaths worldwide, according to the GLOBOCAN database produced by the International Agency for Research on Cancer (IARC).[1] In Germany, about 500,000 people are newly diagnosed with cancer annually,[2] which is the second leading cause of death in Germany and other countries after cardiovascular diseases.[3] Similar to global data, breast cancer is the most common cancer in Germany, accounting for 30% of all new cancer cases among women in 2018.[2] Among men, prostate cancer represents the largest share of new cases at 24.6% in 2018. Other common cancers in both sexes are colorectal and lung cancer, with annual incidences ranging from 9.4 to 13.3.[2] These entities also constitute the largest proportion of cancer mortality. For women, the median age of disease incidence is 69 years and for men, 70 years, with relative 5-year survival rates, adjusted for age and general mortality, above 60% in both groups. The median age at death in Germany is 77 years for female and 75 years for male cancer patients.[2] Children are a separate patient group with other common diagnoses such as leukaemia, lymphoma and brain tumours with much lower incidence rates and higher survival rates[2] and do not pose the focus of this dissertation.

Cancer peer support

Due to more precise and early diagnostics and advanced treatment options[2,4,5] in Germany and other countries with advanced healthcare systems, cancer survival rates have significantly improved. This also means many of the 4.5 million cancer patients and long-term survivors (who often still consider themselves as patients many years after diagnosis of the disease) live with long-term physical, psychological and social consequences of the disease and the late effects of its treatment that they need to manage effectively.[6-8] Besides, the healthcare system poses a challenge due to its complexity, including a variety of different treatment options and pathways.[6-8] To navigate life within and outside the oncological healthcare system, communal, organised peer support is an important pillar for many cancer patients and other chronically ill patients.[9,10] Providing a sense of community, psychosocial relief and addressing unmet support needs of its members relating to their daily life, cancer peer support is a useful and cost-effective complement to professional health care.[9-13] It represents a popular, low-threshold resource offering informational, appraisal, and emotional support for cancer patients and their families.[14,15] Therefore, it has the potential to expand and relieve the already strained health care system and can ease the transition from stationary to ambulatory care.[12] As distinct from professional psychotherapy, psycho-oncological support, counselling, and other psychosocial care services, which are also crucial parts of supportive oncological care, peer support is typically facilitated outside hierarchical relationships by laypersons who themselves are cancer patients or survivors.[12,16] Cancer peer support is mainly held in groups of individuals affected by the same disease on a voluntary basis, but can also be in dyadic settings, both online and in-person. Regardless of whether directly after diagnosis, during treatment or in rehabilitation, research has shown that the exchange between those affected by cancer is often irreplaceable.[10,17,18] Those affected are able to understand each other’s fears or worries, based on their own lived experience, and have a competence through their shared experience that professionals cannot provide, also when dealing with relatives, friends or colleagues.[16,19]

Setting of peer support groups

Peer support groups, often also called self-help groups, are widely established across Germany with a high level of organisation and high volumes of participants. About 100,000 PSGs exist in Germany overall, most of which are predominantly smaller informal groups at a regional level, and nearly 300 more organised health-related peer support organisations (PSOs) at the national level, with subdivisions at the federal state level.[20] Of these, many relate to cancer patients of different entities and also act as a care policy catalyst by representing patients’ interests and their relatives’ needs to improve the quality of care in the professional healthcare system. They participate in research and care in order to advocate for closing gaps in cancer care and actively promote the implementation of the goals and measures of the National Cancer Plan and the National Decade against Cancer *(Nationaler Krebsplan, Nationale Dekade gegen Krebs*).[18,21,22] This, in turn, can improve the quality of life in cancer patients and health outcomes through improved care.[19]

Most of the PSOs are members of nationwide umbrella organisations that represent superordinate collectives. For the range of cancer PSOs in Germany, the House of Cancer Self-Help–Federal Association (HKSH-BV), founded in 2015, is the first umbrella organisation of pharma-independent cancer peer support in Europe.[19] It currently comprises 10 member PSOs that are independent of the interests and financial resources of the pharmaceutical industry and other commercial enterprises in the health care sector. The umbrella organisation and its members are financially supported by the German Cancer Aid (DKH).[19,23] They have voluntarily committed themselves to strict criteria in their cooperation with commercial enterprises. Neither the personal support of individually affected persons nor the representation of interests for all affected persons may be co-determined by business, professional or institutional interests of persons, groups and organisations involved in the care of people suffering from cancer. However, while this independence from commercial interests increases credibility, it can also mean restriction and limiting budgets. Independent PSOs can be recognised by the fact that they transparently disclose their financing and organisational structures and that responsible persons are named. Moreover, no advertising is done for commercial enterprises in the health sector and their donations are not accepted. Yet, several other additional cancer PSOs exist outside the HKSH-BV with different forms of organisation and funding sources. Overall, PSGs are supported by a professional peer support system consisting of more than 300 peer support clearing houses, which maintain additional branch offices providing professional support services for community peer support in 347 locations in Germany.[20] Funding for peer support, of which cancer peer support is a large part, stems mainly from the statutory health and long-term care insurances, the public sector (federal, state and local authorities), and private donors (sponsors and foundations, such as the DKH) next to membership fees.[20] Thus, cancer peer support is a large field of providing support and offering space for the exchange of experiences in different forms and settings across Germany and is increasingly recognised as a crucial part of effective supportive oncological care, as patient participation and patient involvement have become important goals in health care and health care regulations.[24,25]

Peer support integration in cancer care

As a result, the integration of cancer PSGs into oncological care has gained importance in the context of patient-centeredness, and health care decision-makers have made efforts to promote their integration into routine cancer care,[22,26-28] where they work as peer counsellors or as patient representatives to enhance the quality of care. One of these efforts is reflected in the concept of "Self-Help Friendliness in Health Care" developed in Germany and anchored in the award for health care facilities of the "Network for Self-Help Friendliness and Patient-Centredness in Health Care" to strengthen and guide collaboration between peer support and professional health care for a more comprehensive approach to cancer care. A consensus process was launched in 2004 by stakeholders within the German self-help system and representatives of various health care institutions to develop, evaluate and implement quality criteria for reliable, sustainable collaboration between health care institutions and patient groups.[29-31] By now, self-help friendliness (SHF) indicators have been partly implemented in quality management systems in health care institutions and numerous cooperation agreements between hospitals and cancer support groups exist, offering visiting services among others. In 2009, the "Network for Self-Help Friendliness and Patient-Centredness in Health Care" was established as a further development in this process. It currently consists of about 300 members such as umbrella organisations and hospitals and serves as a model for other countries, resulting in the European Action Alliance for Self-help-Friendliness in 2017, including Austria and Switzerland.

Continued efforts are reflected in the quality criteria of the German Cancer Society (DKG), which make the integration of psychosocial care such as PSGs in the German Comprehensive Cancer Centres a prerequisite for certification and funding by the DKH.[22,32] Similarly, closer involvement of peer support is called for in the goals of the National Cancer Plan of the Federal Ministry of Health (BMG).[22] As a result, cooperation between cancer hospitals and PSGs has become more frequent to reach certifications and meet the DKG criteria.[33-35] Moreover, acceptance of PSGs increased among health care workers in cancer care, as illustrated by qualitative research. Yet, integrated care considering PSGs in cancer care has not necessarily become a standard of care, and the extent of integration varies by cancer care facility.[36-40] Thus, albeit a close collaboration is desirable and has been promoted over the past years, its implementation remains fragmented. Although it is important to continue to research and integrate cancer peer support into oncology care, quantitative data on these developments is lacking.

1.1.2. Concept of psychological empowerment

A prominent definition of empowerment guiding this research has been laid out by Zimmerman.[41-43] His theory of empowerment as a multidimensional concept draws on Rappaport's understanding of empowerment as a process "by which people, organizations, and communities gain mastery over their affairs".[44 p.122] It is a perspective that focuses on resources and competencies, rather than patients' deficits and needs, and entails a proactive orientation to managing health-related situations.[44] The concept has its roots in the social action ideology of the 1960s and the peer support perspectives of the 1970s, involving community change, capacity building and collectivity, and was manifested in the Ottawa Charter by the World Health Organization in 1986,[45] illustrating the shift in focus and a new understanding of roles.[46,47]

Zimmerman's theory is based on this perspective and distinguishes between empowerment processes and empowered outcomes. While empowering processes, such as managing resources and learning decision-making skills, describe how people become empowered, empowered outcomes are understood as the effects thereof at the individual level, such as a sense of control and participatory behaviour, which he termed psychological empowerment (PE).[42,43,48] PE is defined by Zimmerman as "a feeling of control, a critical awareness of one's environment, and an active engagement in it"[42 p. 592] and is based on three premises. First, PE varies among people; second, it differs according to the context and life domain; and third, it can change over time. This makes operationalising empowerment challenging, and there are a number of different measures as outlined in previous systematic reviews and discussed below. Zimmerman argues that PE is a dynamic, context-dependent construct rather than a rigid personality trait and therefore a global measure of PE would not be appropriate. Rather, he emphasises the need for context- and population-specific measures, for example, for cancer patients. He proposes a conceptual framework of PE that can guide the development of relevant measures to further inform empowerment theory and to evaluate interventions to improve the empowerment of individuals.[42]

The conceptual framework of PE consists of three components: an intrapersonal, an interactional and a behavioural component (see Figure 1).[42] The intrapersonal component involves self-perception, "how people think about themselves".[42 p.588] It also includes the belief in one's capabilities and the perceived control over one's ability to influence personal circumstances. Therefore, Zimmerman suggests that this component contains perceived control, self-efficacy, motivation to control, perceived competence, and mastery.[42] The interactional component refers to the understanding people have of their environment and the resources it contains necessary to achieve their goals.[42,49] Critical awareness of one's own goals and needs, as well as of the environment and resources, are central to this component, and it states that individuals must first "learn about their options in a given context to be able to exert control in their environment" that is to navigate it.[42 p.589] This component comprises knowledge, decision-making and problem-solving skills and has been extended to health literacy,[42,50] previously defined as "a person's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course”,[51 p.3] or generally as the motivation, knowledge, and competence used to access, understand, appraise, and apply health information and make health-related decisions.[51] The interactional component links perceived control to actual actions taken to exercise control, leading to the behavioural component of PE.[42] The behavioural component includes behaviours to influence outcomes, such as active coping behaviour and participation, e.g. in PSGs.[42,50]

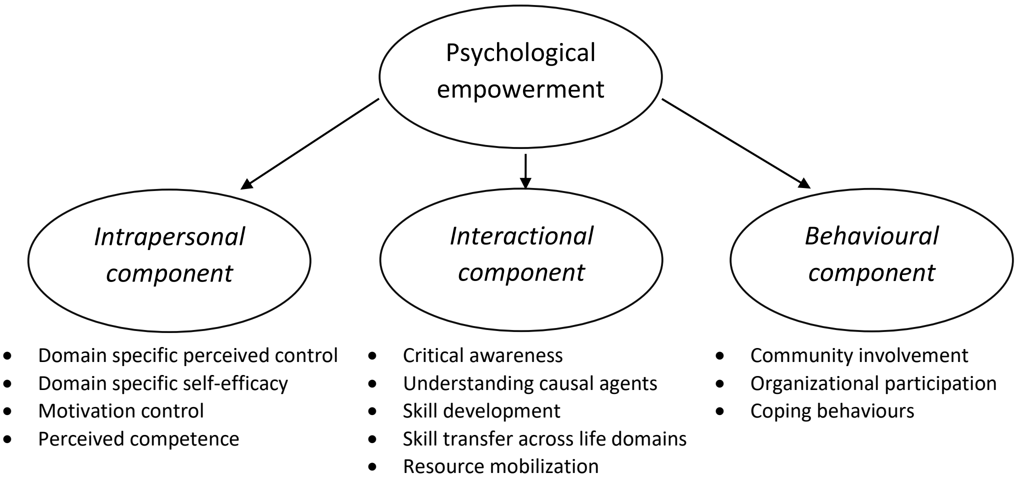

Figure 1: Nomological network for psychological empowerment (Zimmerman 1995, p. 588)

For chronic diseases and conditions such as cancer, empowerment is crucial for patients to cope better with their disease and to find ways and solutions for adequate self-management,[14,52] and has been identified as a key process in recovery.[53] Patients need to navigate complex information within the cancer care system, understand and process disease-related information and medical instructions, to subsequently make informed decisions about their treatment options. Here, disease-specific knowledge is a core component of the interactional component of PE, relevant for making informed decisions which is associated with effective self-management. In turn, it is believed to be associated with improved physical and mental outcomes regarding the course of cancer.[54-57] On the contrary, reduced empowerment in patients, i.e. insufficient personal capabilities to manage medications and side effects, distress, adherence and coping with the long-term burden of the disease, is associated with negative outcomes. Studies have indicated in particular, that many cancer patients lack abilities in the interactional component, such as insufficient cancer-specific knowledge,[55,58-61] or subjectively feel they do not know enough about the complex treatment options, side effects and the oncological care system.[62] This in turn, has implications for patients’ decision-making and the course of the disease,[60] resulting in poorer health outcomes, lower quality of life, higher costs and increased mortality rates.[14,63-66] Along these lines, to help cancer patients become informed “activated” or “expert patients”, effectively managing their disease, empowerment is needed.[42,44]

This definition overlaps with others in that they view empowerment as a multidimensional concept that is essentially concerned with development processes in which people overcome their powerlessness, become aware of their strengths, develop them further and increasingly take control of their own lives.[14,47] The concept of empowerment and citizen participation has highlighted (participation in) PSOs as an important setting for the development of PE.[42,44] It is argued, that peer support is deeply intertwined with the empowerment approach, as peer support is per se a form of empowerment.[67,68] According to Zimmerman’s framework, it is supposed that members of peer support firstly gain the confidence to join a group and develop skills within the intrapersonal component by focusing on their own resources, then acquire knowledge within the interactional component, and eventually develop skills of the behavioural component to cope effectively with their disease over time the longer they are involved in peer support.[42 p.596] Subsequently, through empowerment, peer support can relieve the burden on both the oncological care system and the patients. Hence, its potential role in empowerment as demonstrated in current research is discussed below in more detail.

1.1.2.1. Current evidence on the association of cancer peer support and empowerment

Per definition, cancer peer support is concerned with mutual empowerment and is thus believed to have a complementary role in strengthening patients' empowerment, among other goals.[70-72] It has the potential to empower patients concerning the three components of PE, such as decision-making and other aspects of self-management and coping through informational, appraisal, and emotional support.[9,14,15,52] As a reliable source of direct information for patients it can especially tackle enhancing the interactional component of empowerment through shared knowledge, as typical contents of PSGs are psycho-education about the cancer diagnosis, common experiences with surgery and recovery, and managing side effects.[15,16,18] Additionally, it may increase empowerment indirectly, by enabling participants to become more active patients, to explore more cancer-specific information and to better interact with health care professionals, hence empowering patients in other domains. Cancer peer support, then, also has the potential to encourage and stimulate patients' self-efficacy, improve communication with practitioners and dealing with their chronic illness in their daily lives.

Empowerment through PSGs has often been demonstrated in qualitative studies.[10,14,73-75] A prominent qualitative study by Mok and Martinson[74] identified empowerment as the main theme through participation in PSGs in Chinese breast cancer patients. Another study by Sharf (1979)[76] explored empowerment outcomes of an online breast cancer intervention, and observed connectedness, an internal sense of self, an improved ability to make informed decisions and a resulting ability to take action. Both studies highlight informational support and mutual learning as critical elements of breast cancer support interventions, similar to Gray et al..[75] In addition, qualitative data derived from Stang and Mittelmark[14] identified learning (including consciousness-raising, acquisition of objective knowledge, learning from others' experiences and discovery of new perspectives) as one central element in empowerment processes in breast cancer PSGs. Besides, a current systematic review of qualitative studies by Jablotschkin et al.[77] concluded that participation in cancer peer support led to several perceived benefits of empowerment. In particular, benefits related to the components of PE such as informational support, shared experience, learning from others, helping others as well as cultivating humour as a coping strategy were identified. Similarly, a previous review by Walshe and Roberts[78] emphasised empowering benefits of cancer peer support among qualitative study designs.

However, quantitative evidence on this association is limited, as it is not sufficiently addressed in the current literature. Neither is this association systematically explored by health care researchers within the setting of cancer care, as previous systematic reviews on effectiveness of peer support provide limited evidence or do not focus exclusively on the interplay of empowerment dimensions, cancer and peer support.[10,66,79-88] A systematic review that did focus on peer support and empowerment found significant improvements in empowerment through peer support, however, it did not focus on a cancer population.[66] Other reviews on interventions targeting empowerment explicitly, found positive associations.[81,82,89] Yet, they did not either focus exclusively on cancer but other chronic diseases or not exclusively on peer support. While cancer-specific systematic reviews focused on various cancer entities and peer support interventions exist, they do not assess empowerment outcomes but other psychosocial outcomes.[83-85] On the other hand, studies previously assessing selected empowerment dimensions among other psychosocial outcomes of peer support were limited to one specific cancer entity and provide inconclusive, limited evidence of its effects.[86-88,90] Meanwhile, a systematic review from 2004 discovered informational, emotional and instrumental benefits of cancer peer support programs.[9] Again, it assessed subjectively perceived benefits and suggested the usefulness of participation in peer support, as the patients valued the informational support of PSGs, however, they did not objectively measure its impact on empowerment dimensions.

Overall, current research which systematically assesses the association of participation in cancer peer support with empowerment objectively through quantitative designs, is missing. In particular, little research has been conducted on how cancer-related knowledge as one of the central PE dimensions differs between members and non-members of cancer PSGs, although PSGs seem to be an important resource for improving empowerment. This may be due in part to the fact that measuring PE is challenging. Therefore, the following paragraphs will lay out an overview of instruments and their difficulties in measuring elements of PE.

1.1.2.2. Overview of scales measuring empowerment

As indicated above, measurement of PE poses a challenge, and no established instrument exists that captures the three components of PE and its sub dimensions as a whole for cancer patients across entities. Measuring PE is especially difficult since it consists of multiple dimensions, manifests itself in different perceptions, skills, and behaviours across people and depends on different beliefs, competencies, and actions.[42 p.583] Further, PE may fluctuate over time.[42 p.583] Hence, a range of scales exist, while there is a lack of an inventory containing all potential scales. A systematic review by Eskildsen et al.[50] identified 33 instruments measuring sub dimensions of PE, with only four of these explicitly measuring empowerment among cancer patients in at least two of the three components of PE.[91-94]

The first scale that explicitly assessed two components of PE for cancer, is the 40-item Cancer Empowerment Questionnaire (CEQ).[92] It covers intrapersonal and interactional empowerment skills and is based on the Netherlands Empowerment Questionnaire, showing good psychometric properties. Another scale is the Korean empowerment scale for women with breast cancer by Shin and Park.[95] The validated 30-item instrument contains statements on all three components of PE. Both scales are lengthy, subjective measures suitable for breast cancer patients. The Health Education Impact Questionnaire (heiQ) validated in cancer patients in Canada, includes 25 items on all three components of PE and demonstrated good reliability.[93] The Patient Empowerment Scale (PES) touches on elements of intrapersonal and behavioural components of PE and proved positive values for validity and reliability.[91] Moreover, the Cyber Info-Decisional Empowerment Scale (CIDES) measures perceived empowerment benefits of online support.[94]

Further, several scales exist that focus on single dimensions of one of the PE components. Concerning central elements of the behavioural component of PE, there are more established scales that have been widely used, even though they are not cancer-specific or useable cross-entity. These are scales such as the mini-Mental Adjustment to Cancer scale (mini-MAC),[96] Brief Coping Orientation to Problems Experienced (COPE)[97] or the Functional Assessment of Cancer Therapy (FACT)[98] to measure coping.

Concerning the intrapersonal component of PE, a few established instruments exist, namely, among others, the Cancer Behavior Inventory (CBI),[99] Selbstwirksamkeitserwartung (SWE)[100] scale, the Patient Activation Measure (PAM)[101] and the Communication and Attitudinal Self-efficacy scale for cancer (CASE-cancer)[102] for self-efficacy. The Control Preferences Scale[103] assesses control. All scales contain statements for respondents to indicate their degree of agreement and perceived assessment of PE.

Relating to the interactional component of PE, various measures refer to health literacy, within which knowledge is nested as a central dimension therof. Existing measures assessing cancer-related knowledge such as the Breast Cancer Resources Questionnaire (BCRQ),[104] are predominantly subjective measures containing agreement with statements, rather than objective tests of knowledge.[105-108] Comprehensive objective knowledge tests are scarce and mainly focus on one common cancer entity only,[52,109,110] i.e. breast cancer.[109,110] Other instruments on health literacy show psychometric weaknesses, as demonstrated in a systematic review from 2015.[111] For instance, the 30-item Cancer Health Literacy Test (CHLT-30)[112] is lengthy, and contains a few items irrelevant for cancer patients. The cancer health literacy tool CHLT-6[112] presents a brief instrument appropriate to screen patients with low health literacy, but cannot be used to assess different levels of health literacy among a range of patients. Additionally, some cancer entity-specific scales have been widely used, such as the Literacy Assessment Tool for breast cancer or cervical cancer.[113,114] Other relevant instruments such as the TALKDOC[115] target potential patients. Besides, prominent measures such as the European Health Literacy Questionnaire (HLS-EU Q16)[116] and the Health Literacy Skills Instrument (HLSI-10)[117] are not cancer specific. For relevant sub dimensions of health literacy such as literacy and numeracy, the Test of Functional Health Literacy in Adults (S-TOFHLA)[118] measures reading comprehension/ability, but is cancer-unspecific. The Test for Ability to Interpret Medical Information (TAIMI)[119] and Numeracy Understanding in Medicine (NUMI)[120] tool assess understanding and interpreting medical information, therefore health numeracy. Besides, the Decisional Conflict Scale (DCS)[121] focuses on agreement with statements on decision-making and knowledge about cancer treatment options. Neither of these instruments presents valid, brief and practical measures suitable for objective assessment of cancer knowledge explicitly addressing cancer patients across different cancer entities and contexts of different healthcare systems and taking into account different dimensions of knowledge (i.e. terminology, diagnosis and therapy, prevention, understanding and interpretation of disease-related probabilities, and (socio-) legal aspects), albeit knowledge has been shown to be a central avenue of peer support and empowerment.

1.1.3. Aims and objectives

Against this backdrop, this dissertation follows four specific aims and objectives. With each of these four goals, one research question is associated to which a publication corresponds (see Table 1).

The first aim is to investigate the association of peer support and empowerment within a systematic literature review. Thus, the main research question of the first publication is: *Can participation in peer support programmes promote the empowerment (including knowledge) of cancer patients?*. It is followed by the sub question: *In which dimensions of empowerment does peer support help, to assess if PSGs increase e.g. the knowledge of cancer patients?*. This aim also relates to research question three.

Aim two is to measure cancer-specific knowledge, i.e. to participatory develop a suitable instrument to measure knowledge in a survey with cancer patients. The corresponding research question is: *How can cancer-specific knowledge of cancer patients be measured?* The sub question refers to the psychometric properties of the newly developed scale.

The third aim is to explore the association between peer support and cancer knowledge, with the objective of using and testing the developed instrument in a survey with cancer patients to answer the research question *What is the extent of cancer-specific knowledge among cancer patients, and what are the associations between cancer peer support participation, other relevant variables such as patients' education and their knowledge?.* The sub question is: *To what extent does knowledge about cancer differ between participants and non-participants in cancer PSGs?*.

Lastly, aim four is to assess the integration of peer support and the state of implementation of self-help friendliness in the oncology care system with a survey of cancer PSG leaders. The corresponding publication focuses on the following research question and sub question: *To what extent are PSGs integrated into care? To what extent are self-help friendliness criteria implemented in the oncological care system?*.

Table 1: Overview of the publications

Research questions	Title	Journal	Status	Sample
I) Can participation in peer support programmes promote the empowerment (including knowledge) of cancer patients?	Empowerment in cancer patients: Does peer support make a difference? A systematic review	Psycho-Oncology	published 01/2022	n=29 studies
II) How can cancer-specific knowledge of cancer patients be measured, and what are the psychometric properties of a newly developed instrument for measuring cancer-specific knowledge?	Development and psychometric properties of a brief generic cancer knowledge scale for patients (BCKS-10)	Cancer Causes and Control	published 07/2022	n=500 cancer patients
III) What is the extent of cancer-specific knowledge among cancer patients, and what are the associations between cancer peer support participation, other relevant variables and patients' knowledge?	Do members of cancer peer support groups know more about cancer than non-members? Results from a cross-sectional study in Germany	Supportive Care in Cancer	published 12/2022	n=1,121 cancer patients
IV) To what extent is the integration of peer support in the oncology care system implemented?	Self-help friendliness in cancer care: A cross-sectional study among self-help group leaders in Germany	Health Expectations	published 11/2022	n=266 cancer support group leaders

1.2. Material and methods

1.2.1. Literature review

To inform and complement the two core study modules, a systematic in-depth literature review was completed prior providing an overview of existing studies on the associations of peer support on patient-related outcomes, i.e. empowerment. Hence, the literature review focuses on the research aim I to investigate the effects of peer support on empowerment. A systematic search was conducted within the following databases: PubMed, Web of Science, CINAHL, Cochrane Library, PsycINFO and PSYNDEX databases. Articles published in German or English from the date of inception until December 2020 were considered and screened by three researchers.

Eligibility criteria were developed according to the PICOS framework.[122] Included were quantitative studies focusing on peer-led cancer support interventions and their association with the three components of PE (intrapersonal, interactional and behavioural) among participating cancer patients. Search terms included variants of 1) cancer, 2) peer support group and 3) empowerment dimensions, as stated in Table 2. For data synthesis, the populations, interventions and outcomes of the studies were summarised and described according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.[122] The methodological quality of the included articles was assessed using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies.[123]

Table 2: Search terms and databases searched

Databases searched	Search terms used
PubMed	(cancer OR neoplasm OR tumor OR tumour OR oncology OR oncologic) AND ("self help group" OR "self help organization" OR "self help organisation" OR "collective self help" OR "mutual aid" OR "mutual help" OR "mutual support" OR "support group" OR "peer support" OR "peer counseling" OR "patient organization" OR "patient organisation") AND (control OR "health literacy" OR knowledge OR "self management" OR "self efficacy" OR "health promotion" OR "health behavior" OR "health behaviour" OR prevention OR empowerment OR coping OR competency OR competencies OR competence OR skill OR skills OR ability OR abilities OR "patient participation" OR "patient involvement")
Web of Science (core collection)	
CINAHL	
Cochrane (Trials)	
Ovid Medline (PsycINFO, PSYNDEX)	

1.2.2. Framework project gesa-K

Primary research for this thesis was conducted within the project *gesa-K* (Gesundheitskompetenz, Selbsthilfeaktivitäten und Versorgungserfahrung von Menschen mit Krebs), focussing on health literacy, self-help activities and care experience of cancer patients across Germany, funded by the German Cancer Aid (grant number 70113227). It was based on a participatory research approach and was carried out in cooperation with the HKSH-BV, an association of ten nationwide operating cancer PSOs in the funding period January 2019 to July 2022.

It comprised two modules along the lines of the research questions of this work and uses mixed methods. Module 1 focuses on the experiential knowledge of cancer PSG leaders and, in the form of an explorative observational study, represents the development phase for the patient survey of Module 2, which is concerned with the collection of patients' experiential knowledge. Thus, the project was divided into the following consecutive core elements: Module 1) consisting of qualitative, telephone expert interviews with cancer peer support representatives of the HKSH-BV member associations and a quantitative online survey with cancer PSG leaders on their experiences of cooperation and integration of peer support into the oncological care system as well as on the needs and health literacy of the group participants; and Module 2) containing a quantitative online survey with cancer patients (see Figure 2). Among other things, the interviews served to develop the questionnaire for the PSG leaders, which in turn were used as the basis for the design of the patient questionnaire in Module 2. This concerned in particular the instruments assessing health literacy.

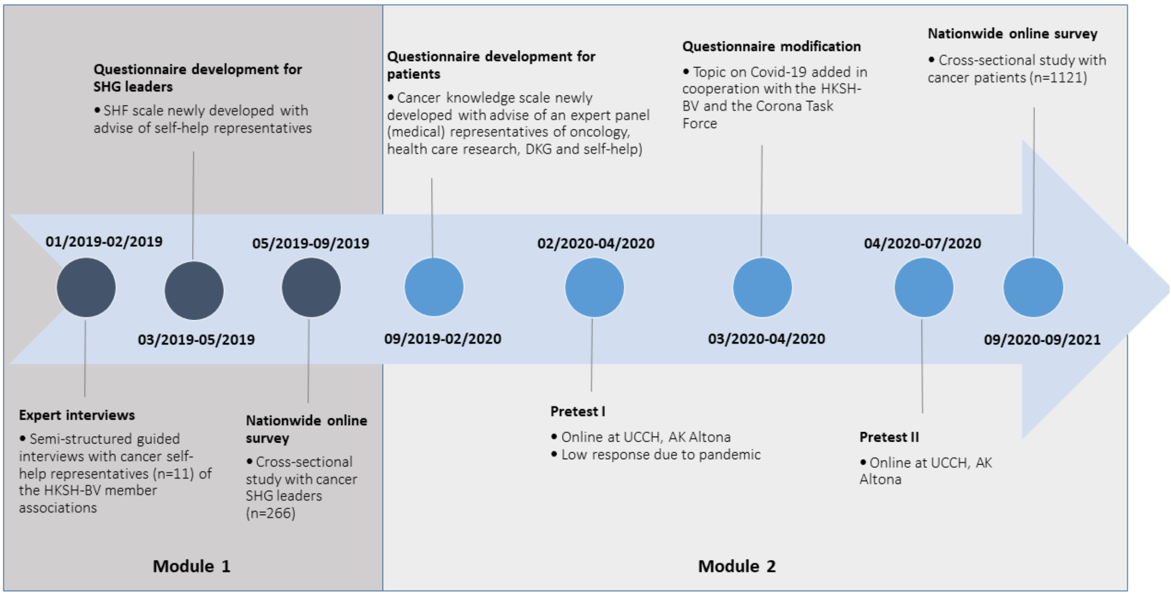

Figure 2: Research process and modules of project gesa-K

The project aimed to investigate cancer patients' self-management and coping with the disease, and to identify factors that promote and hinder high and low health literacy in light of their experiences. In this context, the study sought to provide information on how cancer patients experience and review the communication of the diagnosis, information and education as well as counselling and support in oncological care. In addition, it was of interest which support services are offered to patients and their relatives (e.g. psycho-oncology, social counselling, PSGs, etc.) and whether these are used, how far they are accepted and how they are rated. Hence, the project pursued the goal of mapping the care of people with cancer and their everyday coping in a comprehensive way. Consequently, it aimed to answer the following main questions:

- What experiences do people with cancer have with their (psychosocial) care and how do they evaluate it, what wishes and needs result from this?
- What factors contribute to the health literacy of people with cancer, and what measures (counselling, training, PSGs, etc.) can be used to increase health literacy?
- What are the ways in which people with cancer find their way into cancer PSGs, what are the indicators of peer support activity, what is the contribution of the care system and the cancer centres in mediating people into peer support?
- What effects can PSGs have on the participants, especially with regard to their health literacy?

1.2.3. Study design and samples

An exploratory sequential mixed methods design was deployed, as it is especially useful for developing and testing a new instrument, including qualitative and quantitative research consecutively.[124,125] The initial phase of qualitative data collection and analysis served in particular, to explore the understanding of health literacy and i.e. knowledge from the perspective of cancer peer support representatives. These findings informed the subsequent quantitative phase to develop an instrument for the quantitative phase and to further define central elements of knowledge in a quantitative survey with PSG leaders. It was then used to finally develop and test a knowledge instrument for patients and to eventually measure cancer knowledge among patients.

1.2.3.1. Qualitative

Expert interviews with cancer peer support representatives

Qualitative research was carried out as conceptual preliminary work, to define health literacy and cancer knowledge from the view of peer support representatives and corresponds to the research aim II. The main focus was, among other things, to answer the question of a) which patients' skills and knowledge are defined as crucial from the perspective of cancer PSG leaders regarding health literacy and b) how cooperation and SHF between PSGs and care institutions is perceived. Ten telephone interviews and one face-to-face interview were conducted with PSG representatives between January and February 2019. The interviews were semi-structured guideline-based interviews. Purposive sampling was undertaken,[126] and the selection of interview partners was made selectively based on the expert status and availability of the interviewees, and at least one person from each HKSH-BV member organisation was chosen.

The interview partners were recruited via gatekeeper access through the HKSH-BV and informed by the member associations of the HKSH-BV via e-mail about the expert interviews, passing on the project description and interview structure and asking them to participate. The prerequisite for the participation of the PSG leaders in the interviews was their consent. The interviews were recorded and supplemented by hand transcripts.

1.2.3.2. Quantitative

For the core of this thesis, two nationwide cross-sectional studies were conducted utilising self-administered online questionnaires with the alternative of participating through paper-pencil questionnaires. The surveys were based on a participatory research approach and conducted in cooperation with the House of Cancer Self-Help–Federal Association and its associated member organisations. Prior to data collection, ethical approval was received from the Local Psychological Ethics Committee at the Centre for Psychosocial Medicine, University Medical Centre Hamburg (No. LPEK-0109 and LPEK-0066). Participation in the surveys was voluntary and anonymous. All respondents were provided with forms containing data protection declarations and informed consent before participating. The two modules of primary data collection were complemented by the previous in-depth literature review and culminated in data analyses and publications.

Survey with cancer peer support group leaders

The first survey (Module 1) corresponds to research aim IV, focussing on leaders of different cancer PSGs across Germany to assess the integration of peer support and implementation of SHF in the oncology care system. The questionnaire for group leaders was developed based on the qualitative data of the preceding n=11 expert interviews with representatives of peer support in cooperation with members of the PSOs. The survey was carried out between May and September 2019.

Recruitment of PSG leaders was facilitated via e-mail by the PSOs and also by the regional cancer societies to reach PSGs organised outside the cancer PSOs. The PSG leaders were provided with all relevant project information in the form of a project flyer, including a link to the project website, and a link to the online-survey questionnaire itself. The HKSH-BV sent reminder e-mails to the PSOs and the regional cancer societies.

PSG leaders were eligible for inclusion if they were at least 18 years old, German speaking, with an own history of cancer, leading a cancer PSG of any entity within the HKSH-BV or any other PSG registered at the regional cancer societies in Germany. Targeted were 250 PSG leaders and 266 group leaders participated in the study.

Survey with cancer patients

The second survey (Module 2) was developed based on the previous data collection (i.e. qualitative interviews, the quantitative survey with PSG leaders and a literature screening of instruments). It corresponds with research aims II and III – to develop and implement an instrument measuring cancer knowledge. Targeted were cancer patients of different entities in Germany to investigate the relationship between peer support and cancer-specific knowledge. It was conducted between October 2020 and September 2021.

Patients were recruited through multiple channels, considering 1,382 cancer care facilities for acute, supportive, and aftercare across Germany. The cancer care facilities were informed in advance about the study by post and e-mail. Over 60,000 pamphlets and posters were sent out to regional cancer societies, cancer counselling centres, oncological rehabilitation clinics, certified cancer centres, hospitals with oncological departments, and oncological specialised practices as well as to PSOs providing information about the study and how to participate in the survey. Snowball sampling of patients was also done through the HKSH-BV, PSGs outside PSOs and the German Cancer Society, who were asked to disseminate the call for participation in the study through their communication channels. In addition, study information was published in a newsletter of the National Contact and Information Centre for the Initiation and Support of Self-Help Groups and at a virtual patient congress. To increase participation rates, reminder e-mails were sent in February and May 2021.

Eligible patients were members and non-members of cancer PSGs aged 18 years and older with a cancer diagnosis of any sort and stage. The sample consisted of 1,121 acute patients and cancer survivors across Germany and of multiple entities. Due to snowball sampling, response rates were not determinable.

1.2.4. Instruments

1.2.4.1. Qualitative

Expert interviews with cancer peer support representatives

The guideline for the semi-structured expert interviews was developed using the SPSS method.[127] In addition to introductory questions, it contained open-ended narrative prompts, maintenance questions and concrete follow-up questions on four topics: contents (common goals and topics) of the PSG, health literacy of group participants, cooperation, as well as future perspectives of the PSG. On the topic of "health literacy", the group leaders were asked what patients ought to know and which skills are regarded particularly important for dealing with cancer. In this context, the goal was also to determine which information and factors are helpful for decision-making and interactions with doctors**.** Concerning cooperation, the implementation of SHF was discussed and experiences with cooperation with professionals of oncological care were addressed. The interview guide closed with questions on future development, needs and challenges of peer support and further aspects the interviewees wanted to raise.

1.2.4.2. Quantitative

Survey with cancer peer support group leaders

The group leaders' quantitative survey included questions on eight areas about PSGs: general information about the group, goals and activities of the group, digitisation (use of media, internet, and challenges), access routes to the PSG, needs of the participants, health literacy of the participants, cooperation with health care providers and patient participation in health care/SHF, and activities as PSG leaders. Regarding health literacy of the participants, open ended questions were employed to assess what group members should know about certain cancer-related topics which were assessed as central in the interviews. This thesis focuses on two of these eight topics to answer research question IV, namely access routes to the PSG as well as cooperation and participation as indicators for integration and SHF.

Access routes to the PSG

The PSG leaders were asked to assess on a four-point Likert scale (categories ranging from "very often", "often", "rather seldom", to "(almost) never"), how often patients usually find their way into their group through 11 given channels, such as employees of hospitals and rehabilitation clinics; psychotherapists; homepages of the PSO; social media; family/friends/acquaintances, etc.

Quality of cooperation

Perceived quality of collaboration of the PSG leaders with up to 14 different health care institutions was indicated by respondents on a four-point Likert scale ranging from 1 ("very good") to 4 ("bad"). In instances of institutions that the PSGs did not cooperate with, peer leaders could choose "does not apply". In addition, the questionnaire included two open-ended questions, asking respondents to name facilitating and hindering factors for cooperation between PSGs and hospitals/cancer care facilities from their point of experience.

Self-help friendliness

To assess implementation of SHF as part of the integration of PSGs in cancer care institutions, a modified version of the German survey instrument "Self-help-oriented Patient-centredness" (SelP-K)[128] was used. Here, the SHF criteria served to operationalise the level of integration. The SelP-K instrument contains a 10-item sub scale measuring the indicators for SHF from the view of health care staff with a very good internal consistency of α=0.93 and was adopted for this study. The wording of the 10 statements was transformed from the staff's view about SHF in the hospital into the patients' view of SHF in care facilities. These 10 items represent the quality criteria were presented to the respondents, asking them to state on a four-point Likert scale (from 1 "very true" to 4 "not true at all") the extent of implementation of the criteria. The internal consistency of the adapted scale remained similar (α=0.90) to the original scale.

Global assessment of integration in health care facilities

One single question examined global assessment of integration of PSGs in health care institutions, asking PSG leaders to state how well they feel integrated into care facilities overall ranging on a four-point Likert scale with either "poor", "fair", "good", or "very good".

Survey with cancer patients

The patient survey covered nine topics: diagnosis and treatment, care experience, peer support activity, cancer knowledge, coping and self-management, social support and quality of life, economic situation, religiosity/spirituality, Covid-19 and sociodemographic information. This dissertation focuses on knowledge and sociodemographic information in regard to research questions II and III.

Cancer-related knowledge

A newly participatory developed 14-item questionnaire (BCKS-14) was used to measure cancer-related knowledge as the outcome variable. As an extended version of the BCKS-10, which was validated in a subsample with the first 500 of the 1,121 cancer patients and showed satisfactory internal consistency (Cronbach's α=0.68), it includes four additional nation-specific items about German (social) legislation and patient rights (questions relating to recommended start of follow-up treatment, maximum duration of sick pay, application for a disabled person's card and patients' rights). The scale contains elements of cancer-related knowledge about terminology, diagnosis, treatment, (social) legislation and numeracy/interpretation of disease-related probabilities, which were previously identified as crucial for patients in the studies with PSG representatives and a literature search. The BCKS-14 had similar psychometric properties (Cronbach's α=0.68) as the previously validated BCKS-10. For analyses, correct answers were coded as '1' and both the incorrect and the 'don't know' answers were coded as '0' and a sum score ranging from 0-14 points was built. Consequently, participants could achieve 1 point per correct answer and could reach a maximum of 14 points in case of all questions answered correctly. Up to three missing answers were accepted per respondent which were imputed for building the sum score. If more than three answers were missing, the respondent was counted as missing.

1.2.5. Analyses

1.2.5.1. Qualitative

Expert interviews with cancer peer support representatives

First, the expert interviews were entirely transcribed and anonymised using the transcription programme F4, following Kuckartz,[129] and Dresing and Pehl[130]. The qualitative data analysis was carried out using thematic analysis according to Braun and Clarke.[131] Transcripts were fully considered in the analysis and coded deductively (according to the topics of the guideline), and inductively (from the transcripts) using MAXQDA. Coding units were one complete sentence each and in vivo codes were used, thus the name of the code represented the wording of the transcript. The focus of the analysis was the construction of health literacy and cancer knowledge from the perspective of cancer PSG leaders, i.e. identification of the domain to generate items.

1.2.5.2. Quantitative

Quantitative data analyses were performed using IBM SPSS Statistics 26. The statistical significance was set to an alpha level of 0.05 for all analyses.

Survey with cancer peer support group leaders

Regarding the explorative survey with cancer PSG leaders corresponding with research aim IV, descriptive statistics were used to assess the sociodemographic features of the participants, quality of cooperation and the extent of SHF in cancer care facilities. In addition to descriptive analyses, bivariate analyses were performed to examine correlations with regard to the relationship between the overall SHF score and other variables of interest. For metric and categorical variables cross-tabulation analyses (Eta) were conducted. For ordinal and metric variables Spearman's rho correlations were calculated.

Survey with cancer patients

To test the psychometric properties of the BCKS-10 in the subsample to fulfil research aim II, bivariate analysis was carried out to test correlations between knowledge score and education, and analyses of variance (one-way ANOVAs) were conducted to test knowledge scores and cancer sites. To evaluate reliability, the internal consistency was measured using Cronbach’s α. An item difficulty index ranging from 0 to 1 (high difficulty scores indicate a greater proportion of the sample who answered the question correctly), and the corrected item-total correlation (range from 0 to 1) was used to illustrate the coherence between an item and all other items in the scale. Additionally, the mean score of the BCKS, standard deviation, median, skewness, kurtosis and Shapiro–Wilk-test on normality of distributions were calculated.

For further analysis of the survey with cancer patients concerning research aim III, descriptive statistics were used to examine clinical and sociodemographic characteristics of patients and the distribution of scores of the outcome variables. To evaluate the difference in knowledge scores between PSG members and non-members two-tailed independent t-test was used adjusting for multiple testing according to Holm’s[132] procedure. Besides, t-tests and chi^2-tests were carried out to test for significant sociodemographic and clinical differences among members and non-members of PSGs. Additionally, multiple linear regression was carried out to determine potential associations between knowledge scores, PSG membership, time since diagnosis, internet use, decision-making preference and sociodemographic variables such as gender, age, education and partnership. For analyses, values for decision-making preference and internet use were reversed, PSG membership and partnership were dichotomised, while age and time since diagnosis were coded in years as continuous variables and education was coded into high, medium, and low.

1.3. Results

1.3.1. Empowerment in cancer patients: Does peer support make a difference? A systematic review *(Publication 1)*

The systematic review served to examine if and in which dimensions participation in peer support interventions can promote empowerment of cancer patients and whether PSGs can increase cancer patients’ knowledge. This systematic review assessed different dimensions of empowerment and different types of peer support interventions. Out of n=2,336 screened studies, n=29 met the inclusion criteria and were subsequently included in the review. These were mostly observational studies carried out between 1995 and 2020, involving 12 to 1641 cancer patients and survivors of different entities and ages. The peer support interventions were peer support groups in 17 cases, 11 of which were held face-to-face and varied in duration from at least one session to multiple sessions over 12 months. Besides various study types, interventions and samples, the study quality showed high heterogeneity, and 11 studies were rated as being of moderate quality. Dimensions of empowerment were assessed using a range of instruments, while 9 studies covered multiple dimensions. Of the included studies, 1 assessed control and 9 self-efficacy as part of the intrapersonal component of empowerment; 9 examined knowledge and 4 self-management representing the interactional component; and 12 assessed coping and 2 health behaviour forming the behavioural component, while another 2 studies focussed on overall empowerment.

The majority of studies, constituting two-thirds of the overall findings, showed a significant weak to moderate positive association between participation in peer support and PE. Self-efficacy, knowledge and active coping were found to be key dimensions which accounted for most of the significant findings, covering the three components of PE. The studies demonstrated that peer support interventions can promote empowerment in several dimensions of the three components, consisting of control, self-management skills, self-efficacy, active coping, knowledge and health behaviour. Positive associations were found across different study designs, samples and intervention modalities. As hypothesised, basic peer leader training on communication skills, leadership or cancer terminology as well as experience of the leaders appeared to be beneficial for positive effects. Increased knowledge but also active coping was found even in short-term interventions. In addition, online groups appeared particularly suitable for strengthening coping and dyadic in-person interventions were particularly helpful for improving self-efficacy and knowledge. In less than a third of the studies, no significant associations were observed, and only three negative associations were found in total. Additionally, participation in peer support was associated with substantial patient-reported benefits perceived by patients linked to their well-being, empowerment and encouraging the patient-physician relationship. Thus, the international literature highlights the significance of cancer peer support on empowerment.

1.3.2. Development and psychometric properties of a brief generic cancer knowledge scale for patients (BCKS-10) *(Publication 2)*

As preceding work for research question II on measuring cancer knowledge, results of the qualitative expert interviews focussing on health literacy are presented in the following. The interviewees were 6 federal executive committee members, 2 regional executive committee members and 3 regional group leaders, aged between 47 and 73 years. Six women and five men participated. The interviews lasted between 23 and 60 minutes. Based on the interviews, three overarching dimensions with sub categories were identified, into which health literacy is divided from the point of view of the group leaders: individual skills, health behaviour and knowledge. One of the most important skills identified was the critical handling of information. Emphasis was placed on understanding and weighing information in general and in doctor-patient interaction in particular. Here, the preparation of the conversation and complete and comprehensive information for the patient were highlighted. Self-management and coping were considered equally important. Also, according to the PSG leaders, in addition to optimism and composure, personal inner strength is helpful for the patients, as is overcoming feelings of shame. Acceptance of the disease was deemed important by respondents in order to be able to handle the topic of dying and death. The interviewees also emphasised an open approach to the social environment with regard to cancer and - in the context of peer support - also the exchange with other patients. In the experts' experience, health behaviour includes diet, exercise, and medical monitoring, but also listening to one's own (possibly changed) body.

The following core topics were identified for the knowledge domain central to this thesis: diagnosis and treatment, (social) legal issues complemented by family/personal issues. Concerning diagnosis and treatment, from the PSG leaders' point of view, the main focus is on knowledge about treatment options, the course of treatment and physical changes caused by aids used after treatment, such as artificial bowel outlets or artificial urinary diversions (stomata). In addition to different treatment options such as surgery or chemotherapy and radiotherapy, the interviews illustrated that patients must also know about the latest medical advances, the side effects and the late effects of the therapies. In the opinion of the PSG leaders, it is also crucial to find an individual therapy considering the stage of the disease, its chances and risks, calculation of risk reduction, and the choice of treatment facilities or a second opinion. Above all, the experiential knowledge of others affected was identified by the PSG leaders as important to support the individual therapy decision. Regarding knowledge about (social) legal aspects, benefits of the health insurance funds and other cost units are particularly relevant in the groups, including financial losses (e.g. due to early retirement) as well as the application process, e.g. for a severely disabled person's card and the consequences of a rejected application. The results highlight the relevance for patients to know about information and support possibilities for social legal questions - also for their relatives.

These qualitative findings resulted in generating an item pool containing potentially relevant items for the BCKS development concerning knowledge about diagnostic, treatment, risk factors, early detection, socio-law, claims, rights, (severe) disability, and information sources. Numeracy elements were included as part of knowledge, since calculating risk reduction and incidence rates were also identified as critical elements thereof. Literature research considering (patient) guidelines, DKH guidebooks, literature on oncological surgery and nursing[133,134] and existing instruments complemented these findings to further conceptualise cancer-specific knowledge and to collect suitable questions. For existing scales, the following content-related and psychometric criteria were used to assess the suitability of their items for inclusion in the item pool: language German or English, proven validity and tested in a sample of cancer patients, measuring a dimension of cancer knowledge, low administrative effort and high practicability, brevity (max. 30 items), self-administered and non-computer-based questionnaire, designed for actual patients and applicability across entities. Since no suitable instrument was found, new, own knowledge items were developed and potential items were rated by the project team to prioritise them until a consensus was reached. To reduce and modify the items and to finalise the new scale, an expert panel (scientific advisory board consisting of medical representatives of oncology, representatives of medical sociology, the DKG, peer support research and contact points for PSGs) reviewed the items for appropriateness, adequacy and relevance and tested the scale for face and content validity.[135]

Subsequently, as knowledge has been demonstrated to be a central dimension of empowerment and no appropriate brief scales exist to objectively measure cancer-specific knowledge, the BCKS-14 was developed as a knowledge test containing 14 questions on cancer-related knowledge. For psychometric testing of the 10-item Brief Cancer Knowledge Scale (BCKS), a subsample of n=500 derived from the population described in Table 4. This internationally usable shortened version does not include the four country-specific items on (social) legal aspects. The BCKS-10 score ranges from 0 (very low cancer knowledge) to 10 (very high cancer knowledge), and the mean score was 7.53 (SD=1.98). According to the Shapiro-Wilk test, a normal distribution was given. Analyses of construct validity confirmed previously formulated assumptions, as no significant differences in the knowledge score between different cancer entities ($p=0.288$), and significant positive correlation with education ($p\leq 0.001$) were revealed through ANOVA analyses, supporting construct validity.

The BCKS-10 proved to be applicable independently of the type of cancer. In respect of reliability, the internal consistency amounted to Cronbach's α of 0.68 - an acceptable value for a multidimensional construct of this brevity. Deleting items did not result in improvements in Cronbach's α value. Concerning item discrimination, the item-scale correlation values for the 10 items ranged from 0.24 to 0.41, while the corrected item-total correlation for 8 of the 10 items was >0.3 (see Table 3). Difficulty indices ranged from 43% to 99%. Overall, the psychometric values document suitability of the instrument for assessing patients' generic cancer knowledge across entities.

Table 3: Item difficulty and item discrimination of the BCKS-10 (n=500)

Item	**Item difficulty** (range 0-1)	**Item discrimination** (corrected item-total correlation) (range 0-1)
1. Definition of tumour stage I	0.758	0.322
2. Allocation of 80% drug efficacy	0.876	0.386
3. Meaning of 5% incidence	0.878	0.264
4. Aim of palliative care	0.906	0.414
5. Calculation of risk reduction	0.432	0.348
6. Definition of metastasis	0.990	0.244
7. Definition of cytostatics	0.830	0.413
8. Definition of colonoscopy	0.832	0.336
9. Allocation of false positive result	0.522	0.384
10. Definition of adjuvant therapy	0.502	0.396

1.3.3. Do members of cancer peer support groups know more about cancer than non-members? Results from a cross-sectional study in Germany *(Publication 3)*

To investigate the association between cancer knowledge and peer support participation and to measure cancer-related knowledge among participants and non-participants of cancer PSGs, the newly designed knowledge test was used in a cross-sectional study with 1,121 patients. Female patients accounted for 55% of the respondents, with breast cancer being the most common diagnosis. The patients were on average 61 years old and received their diagnosis on average 5 years ago. Nearly half of the respondents were members of cancer PSGs. Table 4 provides a brief overview of the patients' characteristics (for a full description see publication 3).

Table 4: Sample characteristics of the cancer patients (N=1,121)

Variable	Patients n (%) or Mean (SD)
Age (years)	61.3 (± 12.4)
21-39	66 (5.9%)
40-59	400 (35.7%)
60-79	589 (52.5%)
≥80	66 (5.9%)
Gender	
Male	507(45.3%)
Female	613 (54.7%)
Education	
Low (≤ 9 years)	135 (12.2%)
Medium (10 years)	326 (29.5%)
High (≥ 11 years)	645 (58.3%)
Primary cancer type	
Breast cancer	337 (30.6%)
Prostate cancer	212 (19.3%)
Bladder cancer	91 (8.3%)
Colorectal cancer	77 (7.0%)
Other (overall each less than 5%)	383 (35.3%)
Time since diagnosis	4.6 (± 6.0)
≤ 1 year	345 (30.9%)
1 - 4 years	370 (33.1%)
≥ 5 years	403 (36.0%)
Peer support group membership	
No	600 (54.8%)
Yes	494 (45.2%)

PSG members and non-members in this study showed similar educational levels, decision-making preference, relationship status and internet use for information. Significant difference among both groups were found for age, gender, cancer type and time since diagnosis, with PSG members being mostly males (61.5%) and older (M=65.7), with a diagnosis on average 6 years longer ago (M=7.7) compared to non-members. More PSG members are prostate cancer survivors (30.6%) who completed treatment.

The results present an overall high variance of the knowledge scores, ranging from 2-14 points among PSG members and 0-14 points among non-members. In addition, the examination of significant differences in the mean values of the sum scores (value range 0-14) between PSG members and non-members revealed higher sum scores for PSG members (M=9.94, SD=2.34) compared to non-members (M=8.96, SD=2.79). This difference in the sum scores of 0.97 points on average proved to be statistically significant (95%-CI [0.66; 1.28]), t(1082)=6.25; p<0.001). The difference is also practically relevant as it exceeds the determined minimally important difference (MID) for an estimated small effect size (0.53) considering one fifth of a standard deviation for estimating the MID with a small effect size. Looking at the individual knowledge questions separately and comparing PSG members with non-members, members scored significantly higher than non-members on 7 of 14 items (although with marginal mean differences). It was noticeable that PSG members have better knowledge, especially about definitions and terminology. Differences were also found concerning (socio-) legal aspects, while computational skills (incidence, effectiveness, risk reduction) showed no differences.

In the multivariate regression analyses, controlling for all listed factors as presented in Table 5, education and internet use proved to be significant predictors for increased cancer knowledge followed by membership in a PSG and age, gender and diagnosis period. Precisely, the results demonstrate that younger (β=−0.15; p<0.001), female (β=0.10; p=0.001), higher educated patients (β=0.27; p<0.001) with a diagnosis longer ago (β=0.10; p=0.002) who use the internet frequently for information seeking (β=0.20; p<0.001) and participate in cancer PSGs (β=0.18; p<0.001) had a higher cancer-specific knowledge. Using the BCKS-14, the results demonstrate differences between members and non-members of peer support and suggest that participating in peer support contributes to improving cancer-specific knowledge.

Table 5: Linear regression model examining cancer-related knowledge (n=1,032)

Independent variables	**Regression coefficient B**	**Standard error**	**Standardised regression coefficient β**	**95%-CI**	***p***
Age	-0.031	0.007	-0.152	-0.05--0.02	**<0.001**
Gender	0.535	0.166	0.103	0.21-0.86	**0.001**
Years since diagnosis	0.045	0.014	0.101	0.02-0.07	**0.002**
Education	1.010	0.106	0.273	0.80-1.22	**<0.001**
Partnership	0.056	0.194	0.008	-0.33-0.44	0.773
Peer support group membership	0.915	0.168	0.176	0.59-1.24	**<0.001**
Decision making preference	0.048	0.111	0.012	-0.17-0.27	0.666
Internet use	0.640	0.091	0.203	0.46-0.82	**<0.001**

Significant variables are highlighted in bold

1.3.4. Self-help friendliness in cancer care: A cross-sectional study among self-help group leaders in Germany *(Publication 4)*

To assess if and to what extent peer support is integrated and SHF implemented in the oncological care system, a cross-sectional study with 266 PSG leaders was carried out in Germany, since the previous findings show a positive association between peer support participation and empowerment. Respondents were aged 37 years and older and covered different cancer entities and states. An overview of the sociodemographic characteristics of the PSG leaders in the sample and their corresponding groups is given in Table 6. The existence of the PSGs varied from months up to 49 years (M=16.3 years; SD=11.8 years). The majority of respondents participated in the study via the online survey, and 12 participants made use of the alternative paper-pencil questionnaires.

Table 6: Sample characteristics of the peer support group leaders (N=266)

	Mean	SD
Respondents' age in years	65.5	9.6
Existence of PSG in years	16.3	11.81
	n	**%**
Respondents' gender		
Male	150	56.4%
Female	116	43.6%
PSG member of an PSO*		
Yes	186	69.9%
No	29	10.9%
Cancer entity**		
Various entities	68	25.6%
Prostate cancer	66	24.8%
Bladder cancer	25	9.4%
Colorectal cancer	25	9.4%
Laryngeal cancer	20	7.5%
Thyroid cancer	12	4.5%
Breast cancer	9	3.4%
Pancreatic cancer	8	3.0%
Leukaemia and lymphoma	8	3.0%
Head and neck cancer	7	2.6%
Other	3	1.1%

Abbreviations: N, total number in sample; n, number in subsample; SD, standard deviation; PSG, peer support group; PSO, peer support organisation.(*Note: missing n=51; **Note: missing n=15).

According to the respondents' assessment, 80% of the patients find their way to a PSG primarily through other patients, significantly fewer through staff of health care facilities (50% frequently to very frequently via hospital and rehabilitation clinic staff). In total, 58% of the PSG leaders feel well to very well integrated into health care facilities (scale from 1 (bad) to 4 (very good): M=2.7; SD=0.9). In addition, there are significant moderate to strong correlations between the SHF score and the perceived quality of cooperation. From the point of view of the group leaders, there is a clear potential for improvement between the specialists and psychotherapists in private practice and peer support, as the findings demonstrate that they rarely refer patients to a PSG.

The quality of the cooperation with oncology centres (82% of respondents), hospitals (80%) and rehabilitation clinics (71%) was rated as good to very good overall by the support group leaders. Nine out of 10 quality criteria of the concept of SHF were reported to be fully or at least partially implemented to a large extent by healthcare facilities that are the main cooperation partners of the groups. Here, the values vary between 53% and 87% depending on the quality criterion (see Figure 3).

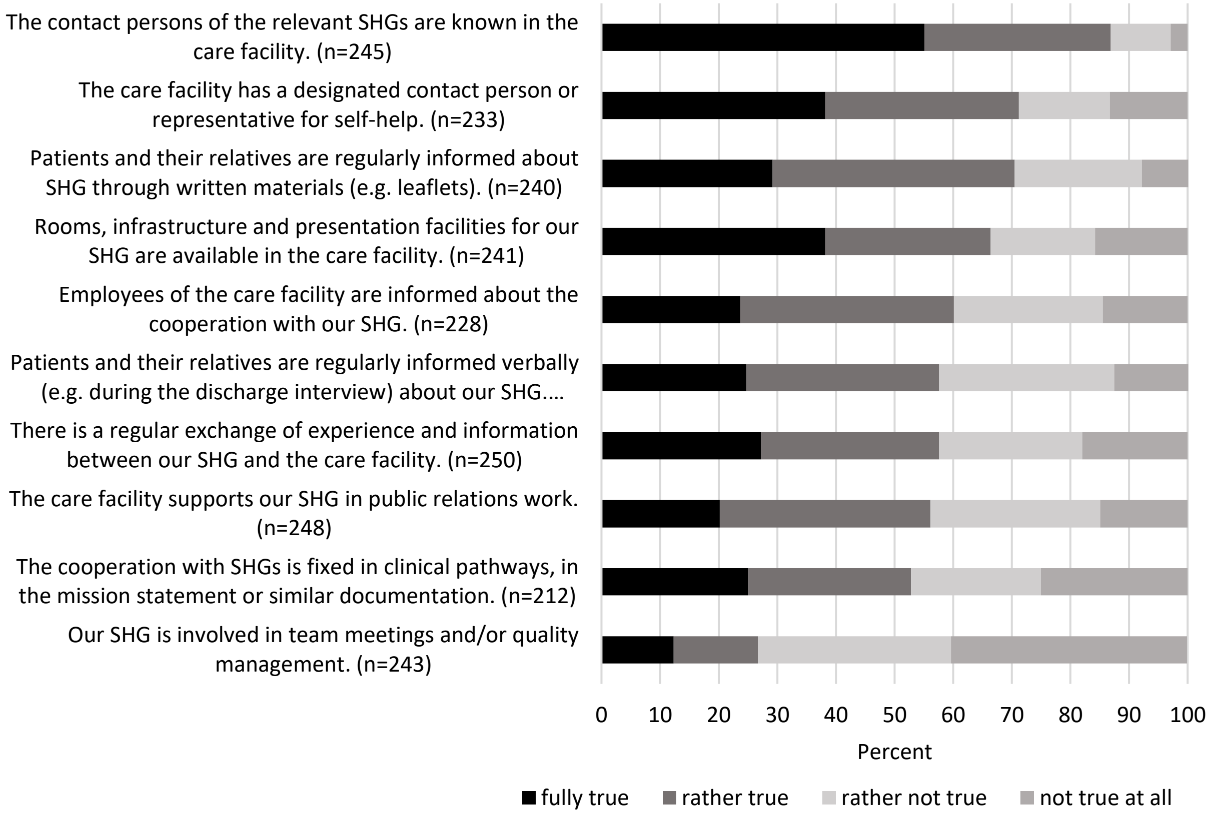

Figure 3: Fulfilment of the self-help friendliness criteria (n=262) *Abbreviations:* SHG, self-help group.

Open-ended questions revealed facilitating and hindering factors for cooperation between PSGs with cancer care facilities. Most identified themes relate to personnel factors and emphasise the importance of human resources rather than formal administrative, spatial or financial factors. The main facilitating factors named were personal contact persons or 'key persons' (n=57), mutual appreciation 'on an equal footing' (n=52), and support for public relations work like distributing pamphlets (n=37). Other facilitating factors were formal and documented cooperation agreements, reliable referral of patients to their groups, and available rooms and infrastructure. The main hindering factors identified were lack of time of staff (n=41), a lack of interest in cancer care facilities (n=34) as well as rejection (n=34), lacking contact and communication (n=22), thoughts of hierarchy and competition (n=22) and ignorance and misconceptions about PSGs (n=22). The results demonstrate an overall positive assessment of the involvement of peer support in oncological care, but highlight differences between inpatient and outpatient care and low referral rates.

1.4. Discussion

1.4.1. Summary and scientific classification in the current state of research

Summary

This dissertation aimed to investigate the association between peer support group participation and empowerment. The findings of this research demonstrated a weak to moderate, positive association between cancer peer support and the three components of psychological empowerment among cancer patients. Knowledge as one element of the interactional component of PE was identified as central for the association of PE and PSG participation. Further, regarding measuring cancer-specific knowledge in the context of peer support, a lack of generic, cross-entity instruments was identified.

Subsequently, zooming in on the interactional dimension of PE, cancer-related knowledge in the context of German cancer care and in the understanding of PSG representatives was participatory defined. It was revealed as consisting mainly of knowledge on diagnosis and treatment and (social) legal issues and led to the development of a new brief knowledge measure. The findings indicate that this newly developed BCKS-10 is a suitable tool to briefly measure cancer knowledge among patients independent of cancer site. Implementing the scale among cancer patients revealed a high degree of variance of cancer knowledge and participation in PSGs as a practical relevant, significant standalone factor being positively associated with cancer knowledge. Accordingly, PSGs were identified as an important element in cancer care and this thesis therefore aimed to assess its integration into routine care. This research found a positive assessment of the involvement of PSGs in oncological care, but differences between inpatient and outpatient care, low referrals and highlighted the need for more systematically integration of peer support in cancer care.

Scientific classification in the current state of research

As part of this research, this is the first systematic review assessing different dimensions of PE and all types of cancer peer support interventions across entities to receive a comprehensive understanding of their interplay. Here, the concept of PE has proved to be a useful approach to assess the potential of peer support reflecting the paradigm shift from patients as agents, considering their resources in cancer care. Using this lens to gather quantitative evidence systematically to close the research gap demonstrated that indeed, participation in peer support interventions can promote the empowerment of cancer patients. It showed that participation in peer support is positively related to all three dimensions of PE within the intrapersonal (especially self-efficacy), interactional (in particular knowledge) and behavioural component (mainly coping). Hence, this research was able to support previous qualitative findings on positive associations between PE and PSGs[77,78] with results from quantitative studies. Besides, given that the majority of studies identified indicated positive associations with small to moderate effect sizes, the results contradict previous studies that found inconclusive, limited evidence of peer support participation and PE dimensions.[86-88,90] The lack of significant negative associations for only peer support participants was noticeable, therefore the findings support previous studies that found no harm in participating in PSGs.[90,136,137]

Concerning characteristics of peer support interventions, no clear commonalities were found, as both online and in-person groups were found to be positively related to PE dimensions, as well as interventions facilitated by trained or untrained peer leaders, and both short-term and long-term interventions. This finding validates significant benefits of PSG participation across different forms of peer support emphasised in earlier systematic reviews.[84,90] Besides, the positive effects found from online peer support in the current review on coping contradict another previous systematic review, which found inconsistent evidence for the efficacy of online peer support interventions for cancer patients.[85] Instead, they underline the notion of other quantitative evidence that online support groups can also contribute to empowerment through sharing information and enhancing coping.[11,17,46,138,139]

Assessing how empowerment and in particular cancer-specific knowledge can be measured, the systematic assessment of the association between peer support and PE revealed a high heterogeneity of measures and highlighted the difficulty to measure PE as a whole. In line with Zimmerman`s understanding of PE as a dynamic, context-dependent construct, most of the identified studies focused on measuring elements of PE in a specific cancer patients sample instead of PE overall. With regard to cancer-related knowledge, it can be defined participatory to be measured. Similarly to the BCKS, existing scales defined knowledge including contents on diagnosis and treatment and aftercare.[52,109,110] Yet, these instruments were specifically tailored to one entity only, lengthy and did not include elements of numeracy, which promoted the need to develop the BCKS as a generic, brief scale. Applying the developed scale in the cross-sectional study among cancer patients found a noticeably high overall extent of knowledge among both PSG members and non-members. Nevertheless, a high variance was visible in both groups considering the relatively low item difficulty and high educational levels of the respondents. These findings suggest that the assumption that many cancer patients have limited disease-specific knowledge, as discussed previously by other authors,[55,58-62] holds true. On the other hand, they may reflect a patients' right and wish to not know disease-related details. Variance within the group of PSG members might also be explained due to the fact that each PSG is different, and which topics are discussed are decided by each group individually, as demonstrated previously.[67]

Moreover, the analyses of the patient survey found a significant difference in the knowledge scores of PSG members compared to non-members. Thus, they support the findings of prior research that concluded that PSGs indeed contribute to extended cancer information among their members.[52,109,110] These results also complement previous findings from qualitative reviews, in which knowledge was identified as a central PE domain in the context of PSG participation (e.g. Holden et al.).[140]

Other potentially influential variables on patients' knowledge were investigated and revealed knowledge scores to be affected the most by the cancer patients' educational levels. This finding is not surprising and confirms previous research findings of patients with higher education holding higher disease-specific knowledge.[57,109] Interestingly, knowledge scores were not affected by patients' partnership status, although previous studies showed that steady relationships or being married as measures of social support can be indicators of cancer knowledge.[141,142] This outcome may suggest that the patients' partners in the current study were not well informed either, or that they have not been sufficiently involved in the patients' cancer history. Yet, their inclusion has the potential to improve knowledge, patient-physician communication and patients' compliance, as they often have more capacities to absorb and remember relevant disease-specific information than the patients themselves, specifically in an overwhelming situation such as a cancer diagnosis.[143,144] This is supported by the finding of higher age being significantly associated with lower knowledge scores in the current sample. Older patients may have problems recalling certain information, effectively communicating with health care providers and obtaining reliable information from the internet.[145] Since internet use was another variable associated with higher levels of cancer knowledge and represented the second strongest predictor as indicated by the beta values, it reflects the notion of the internet being a meaningful source for cancer-specific information. This finding is in concordance with other authors who found internet use of daily internet access to positively impact cancer knowledge.[55,58] The current state of research overall presents mixed evidence on the role of gender on disease-specific knowledge, and some studies indicate higher health literacy scores among male patients.[57] In contrast, in the survey of this thesis, female gender predicted a higher cancer knowledge, however, the association was notably weaker than those of other predictors.

Another patient characteristic found relevant for cancer knowledge was the time since diagnosis. It emerged that newly diagnosed patients held lower cancer-specific knowledge compared to those with a diagnosis longer ago, although Kühner et al.[109] previously reported otherwise. Similar to a study by Fagerlin et al.[58] that identified low knowledge scores among recently diagnosed breast cancer patients, this finding is consistent with the assumption that immediately after diagnosis and in acute care, patients do not necessarily have the capacity to process and take in all information presented by physicians[145] but rather focus on sheer survival and are in a phase of orientation. Subsequently, knowledge increases in the course of the disease and its treatment, and more questions about the disease and its long-term effects such as the probability of recurrence, (socio-) legal matters or dealing with a disability only come into focus in the long run after the first treatment phase or as the patients return to their everyday lives. Thus, in accordance with Zimmerman's[42] suggestion, peer support members first gain the confidence to join a group and develop skills within the intrapersonal component. They then acquire knowledge within the interactional component before eventually developing skills of the behavioural component to cope effectively with their disease over time the longer they are involved in peer support.[42 p.596] Hence, cancer survivors become experts of their illness in the course of time. This is further supported by the fact that patients usually do not join a PSG directly after diagnosis but at a later point in time, as reflected in the patients' characteristics of the cross-sectional study and an earlier study by Stevinson et al.,[146] which in turn can increase cancer-related knowledge further. Nonetheless, this can only be fully grasped through longitudinal study designs.

Assessing the relationships between peer support participation and other influencing variables revealed peer support participation to be an independent factor positively associated with knowledge even after controlling for the socio-demographic factors such as age and education, although not the strongest one. This contradicts the finding of Noeres et al.[110] who noted PSG involvement as the most decisive factor for patients' knowledge and rather reinforces the work of Kühner et al.[109] who reported that the association of PSG membership with cancer knowledge was weaker than the association with other factors. This might stem from the fact that PSGs do not necessarily aim to systematically increase the knowledge of their members, but rather provide informational exchange as one of several other aspects, such as emotional support. Yet, it represents the third strongest predictor of knowledge in the regression model as reflected in the standardised beta values. In addition, the mean score difference among PSG members and non-members was of practical relevance as the 0.97 point difference in the present data exceeds the determined MID of 0.53. Thus, a small effect and a meaningful real-world significance of the differences can be derived from the results. Overall, the results extend previous qualitative research findings, concluding peer support contributes to patients' cancer-related knowledge.

The results also reflect that patients' expectations and wishes of care, e.g. being empowered with knowledge of the disease process and side effects identified by Tuominen et al.[147] can be met through peer support participation. Subsequently, the relevance of the integration of peer support in routine cancer care, the assessment thereof, as well as the lack on research in this field was highlighted. This is the first cross-sectional study of cancer PSG leaders examining the integration of peer support and the implementation of self-help friendliness in the oncology care system. The study revealed a predominantly positive assessment of the integration of peer support and implementation of the self-help-friendliness criteria. However, only half of the respondents reported (very) frequent referral of patients from cancer care facilities into their PSGs, while stressing the importance of reliable referral of patients into the groups as an indicator for successful cooperation. Thus, referral rates were perceived as insufficient and other studies equally reported low referrals from cancer nurses and physicians in hospitals.[36-38] Barriers to referrals despite positive attitudes towards PSGs are grounded in circumstances surrounding the health care system such as limited time of staff,[27,37,148] generally limited staff, unclear responsibilities[36,149] and lack of routine pathways[36,149] along with lack of marketing material such as pamphlets to promote the PSGs within the cancer care facility.[36,40,148] As a result, nurses and physicians often do not recommend PSGs to all patients equally and sometimes misjudge patients' need for peer support.[13,36] Potential reasons for low referral on the patients' end include short duration of patients' hospital stays and being overwhelmed by the abundance of information received in acute care.[148] Important information about PSGs may therefore not be picked up or quickly forgotten by patients, and cancer care staff may not be sure whether or not to provide additional information about PSGs. Moreover, it has been demonstrated by the results that many patients only join PSGs years after the diagnosis, so the referral is likely to come from sources other than acute care facilities. Yet, it is to note that the results illustrate common cooperation between inpatient cancer care units and can be interpreted better than in other indication areas.[39,150]

Also, the satisfying results for the fulfilment of the SHF quality criteria in inpatient cancer care may be expected as many cancer centres in Germany are certified by the DKG and in parallel are similarly audited and certified by the DKH. These certificates require measures for systematic cooperation with PSGs or other psycho-oncological support. Nevertheless, recent audit data from certified cancer centres also reported great differences between centres with regard to cooperation with psychosocial support instances and highlighted similar obstacles to good cooperation.[151]

The current study has brought to light the lack of successful cooperation in particular between PSGs and registered medical specialists and psychotherapists in ambulatory cancer care. This might stem from misconceptions about PSGs and a lack of interest, possibly regarding them as competition or lacking professionalism.[36,38,40,152] This finding confirms previous analyses from Breidenbach et al.[151] who reported shortcomings in psychosocial care for outpatients due to poorer integration, less interest, but also less need for psychosocial care among outpatients. Lastly, outpatients may rather be referred to outpatient counselling centres for psychological therapy.[151] Another reason for lack of collaboration in both inpatient and outpatient care could be the high heterogeneity among PSGs and the already high demand for PSGs while relying on volunteers.

Overall, the results indicate good integration of PSGs in cancer care, even for institutions that do not necessarily use the concept of SHF explicitly. Implementation of all SHF criteria appear to further benefit from long-established groups and relationships, as suggested by the results of the bivariate analyses. Successful integration of PSGs in routine cancer care is certainly, but not only due to certification processes as a commitment to interdisciplinarity,[35] bringing cancer centres and PSOs closer.

1.4.2. Methodological considerations

In the following, methodological reflections and shortcomings of this research are discussed. Concerning the cross-sectional nature of the studies conducted and the majority of observational studies included in the systematic review, it did not allow for demonstration of causality between participation in PSG and cancer-specific knowledge. Consequently, it was not possible to assess how patients process the information received in a support group and to what extent baseline levels of cancer-related knowledge differed between participants and non-participants. However, since no significant differences were found in respect of the educational levels of PSG participants and non-participants and a positive association was found between PSG participation and cancer knowledge, it seems conclusive that PSG participation increases knowledge. This assumption is further supported by the significant mean difference found as well as by the results of the multivariate linear regression analysis, which should also be considered for the association between PSGs and knowledge.

Secondly, the samples studied in this dissertation are not representative, which may impact the validity of the findings. Participants with high levels of education were overrepresented and due to the questionnaire design only literate, German-speaking patients and group leaders participated, while participants with a migration background are underrepresented. Therefore, there could be a bias in favour of positive reporting, and the outcomes in a representative sample with more balanced groups would probably be worse than in the given samples. Such underrepresentation of patients with lower education and migration backgrounds poses a common challenge in survey research. Moreover, mainly patients and group leaders of common entities such as prostate and breast cancer participated, which may have led to further biased results. Nevertheless, due to large sample sizes, the findings can still be regarded as valid.

Additionally, it is noteworthy that no distinction was made between cooperation with DKG-certified and non-certified cancer centres in the survey of group leaders, although certified centres have to cooperate with PSGs for their certification. Also, the positive results may have been overestimated since most of the respondents were leaders of well-established groups that are part of PSGs belonging to the umbrella organisation HKSH-BV. Also, half of the leaders are involved in the certification processes of cancer care units, suggesting that their groups are already highly formalised and professionalised, which in turn is conducive to successful collaboration.

Regarding the BCKS, it is to note that it is generic and does not cover all dimensions of relevant cancer knowledge, but the most important ones according to the PSG leaders. A more extensive, detailed knowledge test including elaborated cancer knowledge, might have led to more apparent differences between PSG members and non-members. Yet, a generic, brief scale was aimed for, and considering that not all PSGs have knowledge transfer as their main objective, the detected difference between members and non-members is more notable. The psychometric testing of the BCKS-10 revealed further limitations. Firstly, two items were below the accepted threshold of 0.3 for item-total correlation[135] (as they were possibly too simple or ambiguous), and secondly, a ceiling effect was assumed given that 15.8% of participants achieved the highest possible score. However, the majority of items were above the threshold and the ceiling effect can be considered minimal, being just slightly above 15%[153] and could be due to the high educational levels of the sample. Since both groups (PSG members and non-members) were equally distributed, this can be regarded as a minor issue. It would have been useful to test for construct validity, however, to compare instruments, no standard measure exists for the German cancer care context.

Unfortunately, for the patients' survey, it was not feasible to determine a response rate or conduct a non-responder analysis. There was no estimated basic population of patients in cancer care facilities, patients were recruited through multiple channels and snowball sampling was employed. Thus, it cannot be tracked which and how many patients were approached and received the call for participation nor how many and which patients refused to participate. Based on experience from other studies it can be presumed that educational bias contributed to non-participation, as patients with low educational levels participate less often in scientific surveys. Moreover, the recruitment took place during the COVID-19 pandemic, which led to less (contact with) patients in cancer care facilities and support groups. Among the PSG members, fewer patients than expected were reached based on the numbers of cancer PSOs in Germany. This might be due to these patient groups receiving a high volume of requests to participate in surveys and other COVID-19 related challenges. Based on this, motivation could have been low and participation in research projects may not have had priority. Yet, as assessed by post hoc power analyses, the sample sizes have sufficient statistical power to analyse, for example, differences between PSG members and non-members or knowledge score differences depending on socio-demographic characteristics such as education. In particular, due to the nearly balanced numerical ratio between PSG members and non-members as well as a balanced ratio between younger and older cancer patients (Mdn=62 years, range=21-90 years), the sample size achieved is sufficient and exhaustive for the analyses undertaken.

1.4.3. Research implications and practice recommendations

Despite methodological challenges, this research produced some valid results from which implications and recommendations for practice can be drawn. These have been partly informed further by exchanges e.g. in the transfer workshop with participants and supporters of the project. Regarding practice in oncological care, it may be helpful for clinicians to regard patient organisations such as PSOs as allies, recognising their potential to inform and accompany patients for a more successful treatment course. Hence, SHF needs to be looked at positively by professionals in order to improve compliance and patient-centred care. The empowerment concept can be a useful approach here, for a resource oriented perspective, taking into account patients' potentials. Since the concept of SHF is a feasible solution for a systematic and measurable integration of PSGs, managers and staff of health care facilities are urged to consider a further implementation to meet the increased demand of patient involvement in cancer care.

Due to the positive association of PSGs with knowledge and the demonstrated clinically relevant difference between knowledge of PSG members versus non-members, the findings shall make it easier for physicians to recommend participation in PSGs for patients to increase their empowerment. This should be done especially for newly diagnosed, older patients with low educational levels, as those were identified as holding lower knowledge levels. Yet, as a high variance of knowledge scores was found among all patients, even those with high educational levels, and knowledge is assumed to be lower among a representative sample, PSGs shall be introduced to all patients.

Besides, as access to PSGs close to the diagnosis is important to make informed decisions about treatment, can improve compliance and was emphasised as crucial by patients, it seems beneficial to appoint a central contact person for patients and PSGs in cancer care facilities. This person needs to be equipped with clear responsibilities to enable referral of patients into the PSGs early on, as early referrals have been successful in improving patient outcomes.[28] Appointing a key person would also promote systematic, regular referral of patients to PSGs, which is often lacking as demonstrated by the results. Those responsibilities must then additionally be stated in disease management programmes or clear referral pathways serving as routine schemes. Consequently, these central contact persons inform patients about PSGs and enable access to the groups, but also coordinate and facilitate communication among PSOs and care facilities to increase patients' awareness of such supportive services.[154] Some hospitals have already implemented such coordinators in the form of “Onkolotsen” or similar key contact persons and established visiting services (“Besuchsdienste”) of the PSGs and have been proven successful to close the gap between PSOs and professionals of cancer care. These efforts should be expanded as part of routine integrated cancer care in all cancer centres to ensure quality care for all patients. Here, sufficient and adequate pamphlets for patient information need to be available in the care facilities.

Since the results imply that knowledge transfer is a central element of peer support fostering empowerment, clinicians are advised to encourage sharing their expert medical knowledge with PSG leaders e.g. through talks and presentations who in turn can circulate the knowledge to their members, ensuring evidence-based factual knowledge. Also, as cancer patients spend more time in rehabilitation clinics than in acute care, the rehabilitation setting could be considered more strongly both by professionals and peer support leaders as another meaningful avenue to introduce patients to peer support. This might be particularly beneficial since most patients join PSGs after acute treatment and may forget information about PSGs in acute care due to the high volume of information, the shock of the initial diagnosis and side effects of treatment. Thus, volunteers may visit rehabilitation clinics for this purpose.

Based on the positive association of peer support and patients' empowerment, systematic integration of PSGs into oncological care as part of routine, quality care and the concept of SHF must be encouraged continuously, especially since its implementation has shown to be heterogeneous. In this regard, concerning cooperation between peer support and professional cancer care, cooperation contracts shall only be concluded by both sides if they can realistically be adhered to. Cooperation has to be lived on by both parties, recognising the potential of PSGs and meeting them at eye level, not using them as an alibi for the own certification interests of hospitals. This in turn would need to be verified more intensively during audit processes for certification, monitoring actual integration and support of PSGs into the cancer centres long-term, which should be enabled by the DKG.

For peer support groups and organisations, it may be helpful to observe referral routes from their new members, in order to evaluate which referral routes need more attention. Moreover, for patients at risk of having low cancer-related knowledge, it is recommended to continuously encourage knowledge gain within the group as a core topic. As part of a joint effort regarding public relations work for the integration of peer support in cancer care, PSGs also need to promote cooperation, e.g. invite clinicians to their facilities, distribute information material about their group, or organise stands at scientific congresses for visibility.

Since a positive relationship between participation in online PSGs as well as internet use for cancer information and empowerment was found, the expansion of innovative, digital services of PSOs is suggested. This would also enable quality care through wider and more flexible access to peer support for a larger number of patients, overcoming spatial distances and physical barriers. Additionally, it is cost-effective and would ensure that patients who look for information online, have access to reliable information. Besides, offering several ways of support ensures that patients have a choice of preference. Along these lines, online PSGs and digitalisation overall need to be perceived as useful complements instead of a threat or competition to existing services. However, these recommendations require more resources from the PSGs, which are already limited, as they are free of charge led by volunteers who are cancer survivors. Therefore, financial support for PSGs must continue to be guaranteed through more subsidies, but also training courses to manage the voluntary, demanding work in the best way possible. Finally, recognition of the potential and the work of PSOs needs to increase to counteract the decline of volunteers and can be represented through subsidies for training courses or travel tickets.

For research practice it is recommended to make use of representative samples and an alternative research design involving multi-arm RCTs with long-term follow-up rates, to elaborate further on the impact of PSG participation and knowledge to verify the results. Yet, it would most likely rely on artificially designed PSGs that do not necessarily represent real conditions. Underrepresentation of patients with lower education and migration backgrounds in survey research should be adequately addressed in future studies by using multilingual and low-threshold questionnaires. To assess the association between PSG participation and knowledge in-depth, other possibly influential factors such as participation in rehabilitation measures or structured treatment programmes need to be considered. Furthermore, the impact of participation in online PSGs versus in-person groups on empowerment can be researched in greater detail. Another interesting avenue for future research would be to examine subjectively perceived and objectively tested knowledge levels simultaneously, to observe how they correspond.

Future studies investigating SHF should differentiate between certified and non-certified cancer centres to evaluate how integration of peer support differs between the two. Also, it could be beneficial to compare SHF in acute care and aftercare. Additionally, future research is encouraged to focus on small, rare cancer entities, as their PSOs may be less likely to be integrated into cancer care. It is lastly recommended for researchers, to discuss and circulate their work (in progress) of their studies with patient organisations and their members, as it has shown to be beneficial in the course of this research. It further enables exchange and motivation and demonstrates appreciation for their participation and work. Similarly, results need to be communicated to clinicians, but also patients and PSOs in layman’s terms, as has been done in the closing workshop, newsletters and the website of the gesa-K project.

1.5. Conclusion

This dissertation has contributed to quantitative evidence for a positive association between participation in cancer peer support and empowerment among cancer patients and to the research on the integration of peer support in oncological care as yet. It has shown that participation in peer support interventions can indeed promote the empowerment of cancer patients and highlighted in particular the positive association with cancer-related knowledge. It demonstrated that cancer-related knowledge can be measured considering a participatory understanding of relevant contents with a newly developed, brief tool across entities. Using the tool revealed a high variance of cancer-related knowledge among all cancer patients and further confirmed more pronounced knowledge among patients participating in PSGs. The results emphasised that PSG membership is a significant, independent factor contributing to higher cancer-specific knowledge among education, internet use, age and gender, albeit not the most decisive. This research illustrated that peer support is overall well, but not yet sufficiently systematically integrated into oncological care. Subsequently, this research concludes by stating that peer support is an important element in cancer care that needs to be promoted and integrated further into routine cancer care, requiring additional resources to enable comprehensive cancer care that is consistently (cost-)effective, patient-centred and of high quality nationwide across care facilities.

Thus, the task for health policy remains to use existing structures more effectively and to equip the current system with resources such as central contact persons for patients and peer support, clear pathways and responsibilities and by means of the SHF concept to realise the integration of peer support in oncology care facilities. Here, peer support integration needs to be facilitated along professional psycho-oncological support services as part of routine care, acknowledging their potential to positively impact empowerment and in particular patients’ cancer-related knowledge, without overburdening the voluntary lay peer support system.

2. List of tables/figures

3. List of abbreviations

PSG	peer support group
PE	psychological empowerment
IARC	International Agency for Research on Cancer
PSO	peer support organisation
HKSH-BV	House of Cancer Self-Help – Federal Association (Haus der Krebs-Selbsthilfe Bundesverband)
DKH	German Cancer Aid (Deutsche Krebshilfe)
SHF	self-help friendliness
DKG	German Cancer Society (Deutsche Krebsgesellschaft)
BMG	Federal Ministry of Health (Bundesministerium für Gesundheit)
CEQ	Cancer Empowerment Questionnaire
heiQ	Health Education Impact Questionnaire
PES	Patient Empowerment Scale
CIDES	Cyber Info-Decisional Empowerment Scale
mini-MAC	mini-Mental Adjustment to Cancer
COPE	Brief Coping Orientation to Problems Experienced
FACT	Functional Assessment of Cancer Therapy
CBI	Cancer Behavior Inventory
SWE	Selbstwirksamkeitserwartung
PAM	Patient Activation Measure
CASE-cancer	Communication and Attitudinal Self-efficacy scale for cancer
BCRQ	Breast Cancer Resources Questionnaire
CHLT	Cancer Health Literacy Test
HLS-EU	European Health Literacy Questionnaire
HLSI	Health Literacy Skills Instrument
S-TOFHLA	Test of Functional Health Literacy in Adults
TAIMI	Test for Ability to Interpret Medical Information
NUMI	Numeracy Understanding in Medicine
DCS	Decisional Conflict Scale
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
EPHPP	Effective Public Health Practice Project
gesa-K	Gesundheitskompetenz, Selbsthilfeaktivitäten und Versorgungserfahrung von Menschen mit Krebs
BCKS	Brief Cancer Knowledge Scale

SelP-K	Self-help-oriented Patient-centredness
MID	minimally important difference
SHG	self-help group

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5. Publication 1

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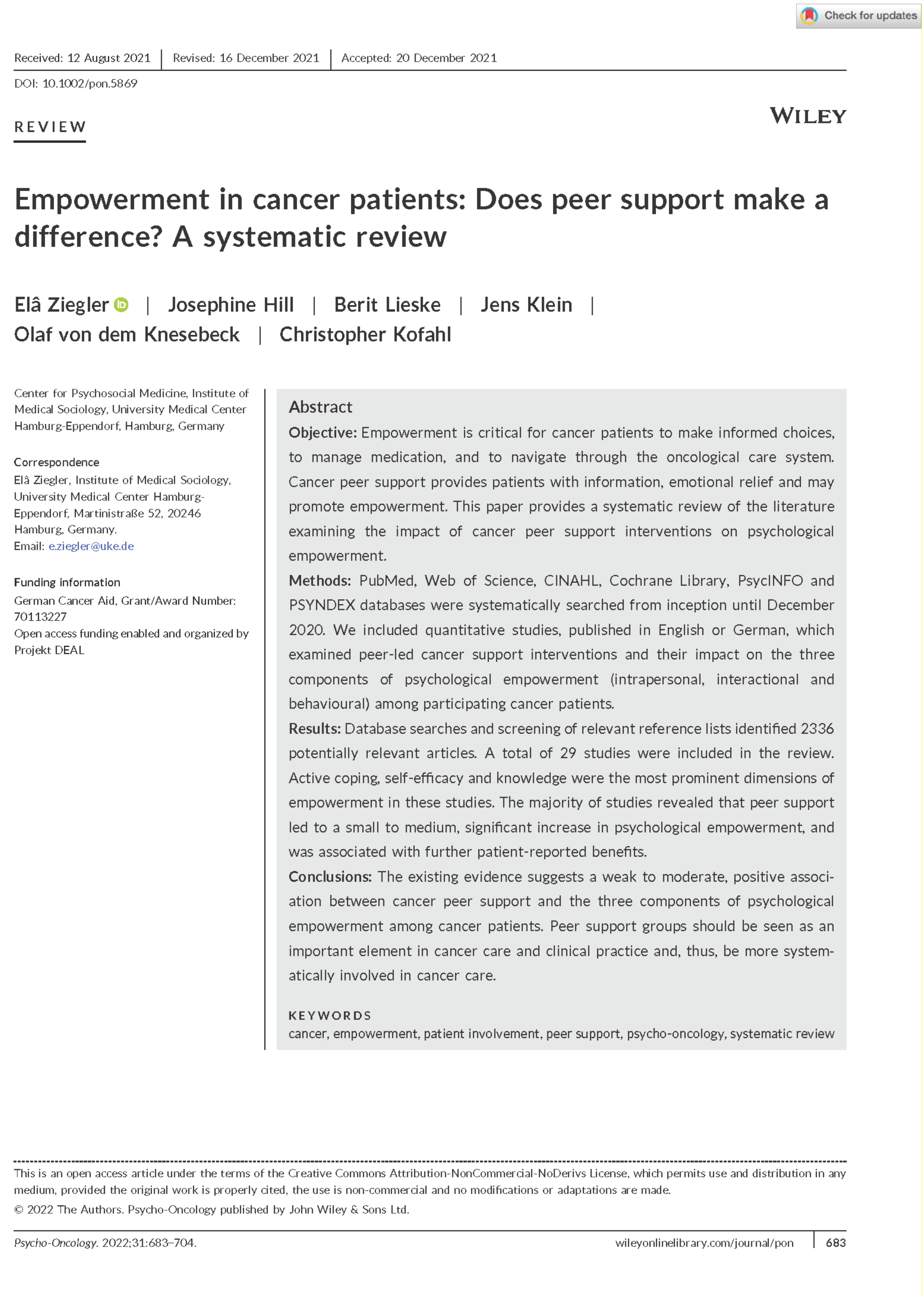

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REVIEW

Empowerment in cancer patients: Does peer support make a difference? A systematic review

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Abstract

Objective: Empowerment is critical for cancer patients to make informed choices, to manage medication, and to navigate through the oncological care system. Cancer peer support provides patients with information, emotional relief and may promote empowerment. This paper provides a systematic review of the literature examining the impact of cancer peer support interventions on psychological empowerment.

Methods: PubMed, Web of Science, CINAHL, Cochrane Library, PsycINFO and PSYNDEX databases were systematically searched from inception until December 2020. We included quantitative studies, published in English or German, which examined peer-led cancer support interventions and their impact on the three components of psychological empowerment (intrapersonal, interactional and behavioural) among participating cancer patients.

Results: Database searches and screening of relevant reference lists identified 2336 potentially relevant articles. A total of 29 studies were included in the review. Active coping, self-efficacy and knowledge were the most prominent dimensions of empowerment in these studies. The majority of studies revealed that peer support led to a small to medium, significant increase in psychological empowerment, and was associated with further patient-reported benefits.

Conclusions: The existing evidence suggests a weak to moderate, positive association between cancer peer support and the three components of psychological empowerment among cancer patients. Peer support groups should be seen as an important element in cancer care and clinical practice and, thus, be more systematically involved in cancer care.

KEYWORDS
cancer, empowerment, patient involvement, peer support, psycho-oncology, systematic review

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1 | BACKGROUND

As a result of increasing survival rates in countries with advanced health care systems, many cancer patients are faced with long term consequences and the complex challenge of choosing among different treatment options.[1,2] Empowerment is crucial as patients need to understand and process disease related information and medical instructions in order to make informed decisions regarding their treatment options, and to navigate successfully through the oncological care system.[3,4] Yet, many patients do not have sufficient personal capabilities to manage medications and side effects, distress, adherence and to cope with the long term burden of the disease.[3,5–7] This, in turn, leads to poorer health outcomes, higher costs and increased mortality rates.[6–9]

Empowerment is a multidimensional concept that is concerned with people's development processes to overcome powerlessness, become aware of their strengths, and take control of their own lives.[5,10,11] In patient-provider relationships, empowerment is central in moving patients towards becoming informed "activated" or "expert patients".[3,12–14]

In 1986, the WHO Ottawa Charter highlighted the necessity to focus on resources and competences rather than on deficits and needs of patients.[15] Empowerment focuses on such competencies, entailing proactive management skills to deal with health related situations.[16–18] The empowerment concept is rooted in the 1960s ideology of social action, which embraces community change, capacity building and collectivity. According to Rappaport, empowerment is a process "by which people, organizations, and communities gain mastery over their affairs".[13(p. 122),14,16,19]

Drawing on Rappaport,[13] Zimmerman has provided a theory of empowerment which is well established.[14,19] His theory differentiates between empowerment processes and empowered outcomes.[14] Zimmerman describes empowering processes as managing resources and learning decision making-skills and understands empowered outcomes as the consequences thereof, such as sense of control and participatory behaviour, which he termed psychological empowerment (PE).[14,20] PE is defined as 'a feeling of control, a critical awareness of one's environment, and an active engagement in it'[14 (p. 592)] and is founded on three premises. First, PE differs across people, second, it differs across contexts and life domains, and third, it may change over time.[14,18] This makes the operationalisation of empowerment challenging, and a range of various measures exist as illustrated in previous systematic reviews.[11,21–23] Zimmerman argues that a global measure of PE would not be appropriate. Instead, he emphasises the need for context- and population-specific measures.[14]

Zimmerman's conceptual framework of PE consists of three components which are relevant for the development of specific measures. (1) The *intrapersonal* component is concerned with self-perception and therefore contains perceived control, self-efficacy, motivation to control, perceived competence, and mastery.[14] (2) The *interactional* component refers to people's critical awareness of their environment and its resources to achieve their goals.[14] It helps individuals to 'learn about their options in a given context in order to be able to exert control in their environment'.[14(p. 589)] This includes knowledge, decision-making and problem-solving skills, which is closely related to the later concept of health literacy.[11] (3) The interactional component links perceived with exercised control, hence, forming the *behavioural* component of PE, containing active coping behaviour and participation for example, involvement in peer support groups (PSGs).[11,14]

The concept of empowerment and citizen participation has brought peer support organisations to the centre stage for developing PE.[14,16,19] Cancer peer support provided in groups or dyads of individuals with the same disease who meet outside professional settings and hierarchical relationships can empower cancer patients by providing informational, appraisal, and emotional support.[6,24] According to Gray et al., PSGs are 'concerned with participant empowerment and democratic decision-making'[25(p.245)], and Mead et al. view peer support as 'a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful'.[26(p.135)] The Stone Center terms this concisely as 'mutual empowerment'.[27] Thus, one important task of peer support is to empower patients in decision-making and other aspects of self-management and coping.[6,14,24]

Empowerment through PSGs has often been demonstrated in qualitative studies.[6,28–31] Quantitative evidence regarding the association between peer support participation and empowerment in cancer patients, however, is rare. Previous systematic reviews on effectiveness of peer support provide limited evidence or do not focus exclusively on empowerment dimensions, cancer and peer support.[10,32–40] Therefore, the aim of the present systematic review is to provide an overview of findings from observational and interventional studies regarding the association of participation in cancer PSGs and/or dyadic peer support with the empowerment dimensions as defined by Zimmerman.

This review has conceptually been guided by three preliminary considerations. Firstly, untrained peer leaders often feel overstrained in meeting the complex needs of leadership.[41] Therefore, peer leader programmes aim to equip them with adequate skills to facilitate a peer support intervention.[42] This paper aims to explore the impact of such peer leader training on empowerment outcomes in cancer patients. Secondly, outcomes in the behavioural component of PE may become visible only after long-term peer support participation. Possible benefits are growing step by step in these dynamic processes, and, according to Zimmerman's theory, first in the interactional component and last in the behavioural component. This review assesses possible associations between the length of a peer support intervention and different outcomes in PE. Thirdly, online peer support offers an alternative to 'classical' face-to-face peer support. While research suggests that face-to-face groups are often preferred,[35,43] online peer support is still growing in popularity, indicating that it meets the demands of those concerned. However, it remains unclear whether online peer support is as effective as in-person peer support and whether they are equally suited to enhance all components of PE. Thus, this review will assess which modes of delivery of peer support foster specific outcomes of PE.

2 | METHODS

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[44] It was prospectively registered on the National Institute for Health Research International Prospective register of Systematic Reviews (PROSPERO) (CRD42020154856).

2.1 | Eligibility criteria

The following eligibility criteria were considered according to the PICOS framework:[44,45]

Participants: All cancer patients across all ages with a current or previous cancer diagnosis of any site were included.

Interventions: Peer-led cancer support interventions, defined as a direct self-help group or dyads with the primary purpose of providing support to people with cancer, were considered for this study. The cancer support intervention must be facilitated by peers (i.e. people who have been diagnosed and/or treated for cancer) only. The intervention can be delivered individually or in a group and facilitated through the following media: online, in person, or via phone. Other combined interventions as well as psycho-oncological interventions led by professionals, schooling programs, online web pages without interactive components or support groups targeted at relatives of cancer patients only were excluded. If there was a lack of information on group leaders, or if the composition of the group was not specified, studies were not included.

Comparators: Non peer-led support interventions and other psychosocial interventions served as control groups for studies comparing different interventions. For comparative studies with only peer support as the single intervention, control groups were cancer patients who have not participated in a PSG or in dyadic peer support. Studies without a comparison group were also included.

Outcomes: In accordance with Zimmerman's concept of PE, measures and observations indicative of the three components of PE were considered. Thus, eligible outcomes for this study with regard to the intrapersonal component were control and self-efficacy. For the interactional component, knowledge, skills and competencies, health literacy and data on self-management were included, because its core skills are problem-solving, decision-making, and resource utilisation, and was therefore judged elementary for the interactional component of PE.[3,11,14] For the behavioural component, patient participation and involvement, active coping, health prevention, and health promotion behaviour of cancer patients were considered.

Study designs: All types of quantitative studies and mixed methods studies containing a distinct quantitative component that is presented separately were considered. Only papers describing original empirical research were included. Case reports, comments, conference abstracts, study protocols, or dissertations were excluded as well as reviews, editorials, and purely qualitative studies.

2.2 | Databases and search strategy

Searches were conducted within the following databases: PubMed, Web of Science (Core Collection), CINAHL, Cochrane Library, PsycINFO and PSYNDEX (via Ovid). Additionally, supplementary searches were performed by hand of reference lists of relevant reviews and included studies (backward searches). German and English-language articles published from date of inception until 31 December 2020 were included. A combination of medical subject headings and keywords was used for the search strategy, as described in Table S1.

2.3 | Data extraction (selecting and coding)

Search results of all databases were merged and duplicate records were removed using the reference management software EndNote. Titles and abstracts of all entries were firstly scanned independently by three reviewers (BL, JH and EZ) to determine study eligibility after piloting the extraction criteria. In 86% of the cases all reviewers agreed to either include or exclude articles for title-abstract screening. Whenever all three reviewers did not agree on inclusion, a decision was made by the majority principle. Only reports that clearly failed on one or more of the inclusion criteria were excluded at this stage. Any discrepancies and disagreements were presented at regular meetings and resolved through discussion.

At the second stage, full texts were obtained, organised within the reference management software EndNote to identify relevant studies for data extraction, read by all three reviewers and final decisions on study inclusion were made. If a study was not included, the reasons for exclusion were reported. Interrater-reliability was high - in 91.5% of the cases all three reviewers agreed on the exclusion of an article, and in 70% of the cases all three reviewers agreed on both the exclusion of an article and the exclusion criteria. Disagreements about exclusion criteria, and the eligibility of an article were resolved according to the majority principle. If all three reviewers disagreed on exclusion criteria, the disagreements were resolved through discussion and a joint decision was reached.

The screening of full texts revealed substantial clinical and methodological heterogeneity of the included studies and therefore precluded conducting a meta-analysis. For a meaningful meta-analysis the differences in study designs and intervention duration were too large, the same parameters of interest measured too broad, and concerning meaningful subgroups (e.g. health behaviour in randomised controlled trials [RCTs], $n = 1$) the number of studies was too small. Instead, a narrative synthesis was conducted.

2.4 | Quality assessment (Risk of bias)

The quality of the studies was assessed using the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies (EPHPP)[46] as it applies to a wide range of quantitative research.[47] Each study was evaluated according to six components: selection bias, study design, confounders, blinding, data collection methods, withdrawals and drop-outs. In addition, intervention integrity and analyses were assessed, but were not considered for the global rating according to the tool. Component ratings of ‘strong’, ‘moderate’ or ‘weak’ were applied as well as an overall global study quality rating based on the combination of ratings. A global ‘strong’ rating was assigned when no component was rated as ‘weak’, a ‘moderate’ rating indicates that one component was rated as ‘weak’, and a ‘weak’ rating was derived when two or more components were categorised as ‘weak’. Whenever there was too little information provided on the individual components, they were rated as ‘moderate’. After a pilot rating, the three assessors (BL, JH and EZ) independently rated each study for study quality. Differences were resolved through discussion comparing individual ratings to reach consensus. All studies were included to the narrative synthesis.

3 | RESULTS

A total of 2336 articles were assessed after duplicates were removed. The PRISMA flow diagram was used to report the study selection process as shown in Figure 1.[44] In all, 29 studies were eligible for inclusion, summarised in Table 1. Three articles were excluded after full-text screening, because they presented the same data of a sample that had previously been published.[50,55,76] These articles were used as additional references for further information on the studies.[77–79]

3.1 | Study characteristics

Eleven of the studies were conducted in the United States, the remaining studies in Germany, Denmark, England, China, Netherlands and Korea. Twelve experimental studies, one quasi-experimental study and 16 observational studies were found. Eleven studies were cross-sectional, six of them included a comparison group. Ten studies were RCTs, including one feasibility study for a RCT. All RCTs collected data at baseline and nine of them collected data on at least two follow-ups, ranging from one to 12 months after the intervention. Sample sizes ranged from 12 to 1641 participants. Two thirds of the studies had an overall sample size of at least 100 participants. Ages ranged from 18 to 83 years. Most participants were patients with breast cancer.[48,49,51–53,56,57,59,60,62,63,66,71–73] Other cancer types included prostate cancer[50,55,58,75,76] and throat cancer.[68] One study focused on leukaemia patients[64] and seven studies on various cancer sites.[54,61,65,67,69,70,74] The patients' stages of cancer and time since diagnosis varied. Six studies included newly diagnosed patients (<3 months since diagnosis).[52,53,60,64,65,75] In four studies the average time since diagnosis ranged from 3 to 12 months,[50,62,66,67] in five studies from 1 to 3 years,[51,61,69,70,72] in three studies from 3 to 6 years,[59,63,73] and in three studies from at least six years.[54,55,58] Two studies included survivors without specifying the time since diagnosis.[48,57] Study characteristics are summarised in Table 1.

All interventions were delivered by non-professional peers only, who in 11 studies received training in communication skills, leadership training, or basic cancer terminology.[50,52,53,58,60,64,65,71,74–76] The peer support interventions were mainly held in group settings (17 studies), of which 11 were face-to-face group interventions[48,51,54,55,58,59,61,63,67,68,72] and seven were delivered online.[56–58,66,69,70,73] Twelve peer interventions were one-on-one, mostly conducted face-to-face, but also by telephone, or–in two cases–via e-mail.[49,50,52,53,60,62,64,65,71,74–76] If provided, duration of counselling varied from at least one session to several sessions within 12 months. The frequency of interactions was weekly in at least three studies, while most others had different intervals.

The included studies used diverse instruments to measure different dimensions of empowerment (Table 1). Twelve assessed coping (using mini-Mental Adjustment to Cancer (mini-MAC) scale, Brief Coping Orientation to Problems Experienced (COPE), Dealing with Illness Inventory-German Revised (DWI-GR), Functional Assessment of Cancer Therapy (FACT), Electronic Cancer Coping Scale (ECCS)),[49,51,54,56,57,60–62,67,69,70,74] nine assessed self-efficacy (Cancer Behavior Inventory (CBI), Stanford Inventory of Cancer Patient Adjustment (SICPA), General Self-Efficacy Scale (GSE), Stanford Emotional Self-Efficacy Scale–Cancer (SESES-C), Self-Efficacy Scale for Self-Management of Breast Cancer (SESSM-B), Selbstwirksamkeitserwartung (SWE) scale, Cancer Management Self-Efficacy Scale)),[48,52,53,60,64–66,75,76] nine assessed knowledge (Breast Cancer Resources Questionnaire (BCRQ) and newly developed questionnaires),[52,53,55,58,59,61–63,71] two assessed empowerment (Cancer Empowerment Questionnaire (CEQ) and modified own items),[72,73] four assessed self-management skills,[55,58,64,71] two assessed health behaviour outcomes[50,68] and one assessed control.[58] No study assessed health literacy explicitly. Nine studies examined more than one dimension.

3.2 | Quality assessment of studies

Study quality was deemed as ‘weak’ for nine studies,[54,58,59,61,63,69,70,72,73] moderate for 11 studies,[48,50,55,56,62,64–66,68,71,74] and ‘strong’ for nine studies[49,51–53,57,60,67,75,76] (Table S2).

3.3 | Peer support and empowerment

3.3.1 | Empowerment

Two observational studies[72,73] were found, in which the associations between PSG participation and overall empowerment were examined. As reported in the study of Shin and Park, PSG participants showed a moderately higher level of empowerment than non-participants ($p = 0.002$), and their empowerment level and quality of life

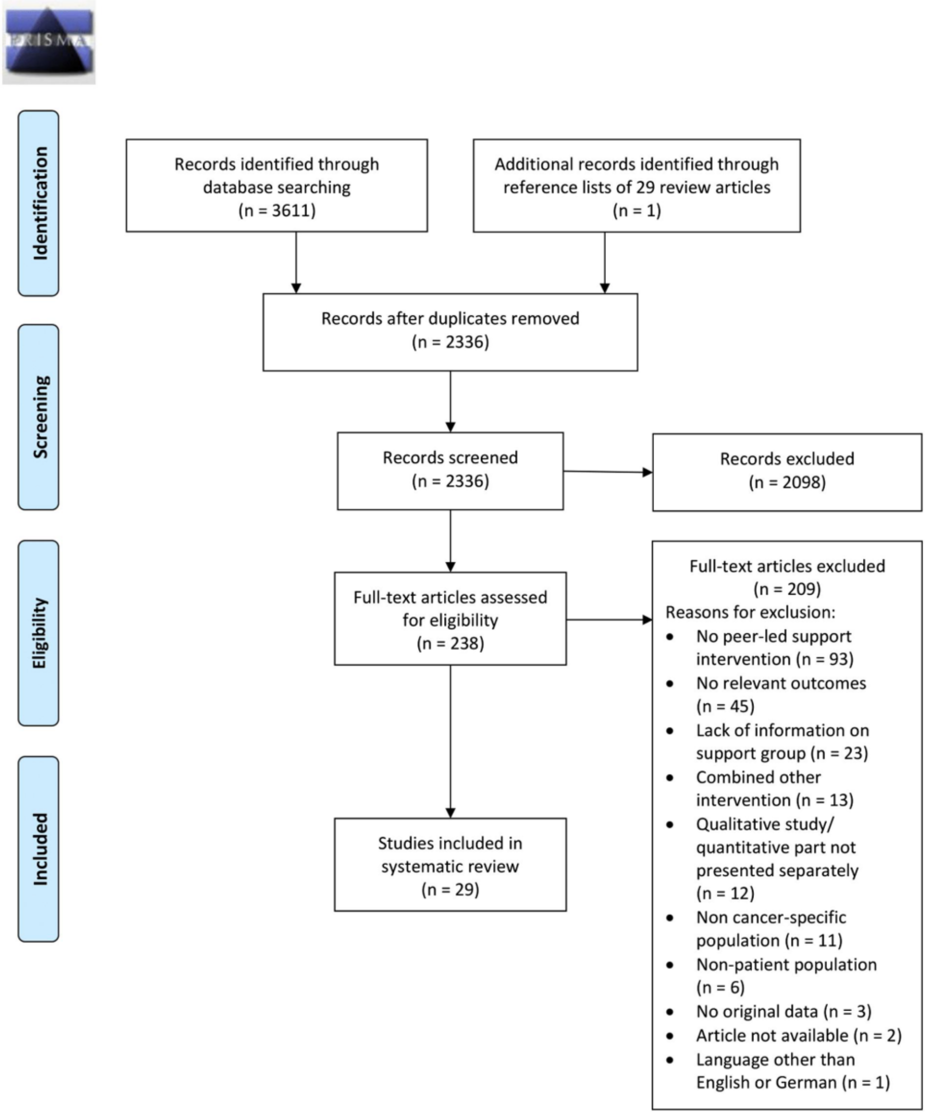

FIGURE 1 Preferred reporting items for systematic reviews and meta-analyses flow diagram of study selection process

showed a strong positive relationship ($p < 0.001$).[72] Further, they found a moderate interaction between empowerment and group participation ($\beta = -0.26$, $p = 0.048$). According to a cross-sectional study of breast cancer PSG participants without a comparison group, the participants of an online PSG felt empowered in several areas - the strongest perceived changes were in 'being better informed', 'enhanced social well-being' and 'feeling more confident in the relationship with their physician'.[73]

3.3.2 | Intrapersonal component

We identified 10 studies that assessed PSG participation and outcomes of the intrapersonal component of PE. Six of these found positive associations with small to medium effect sizes.[52,58,60,65,75,76] The other four studies did not find any effects and none of the studies reported negative effects.[48,53,64,66] The results are presented in more detail below and in Table 1.

TABLE 1 Summary of study characteristics and main outcomes

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
Antle and Collins[48]	US	Quasi-experimental (interrupted time series)	41 female PSG participants with breast cancer, mean age 58.16 years	Group, face-to-face, 10 months (One session per month)	No	Self-efficacy: Cancer management self-efficacy scale	A significant positive correlation between spiritual well-being and cancer management self-efficacy among PSG participants ($r = 0.292$ $p < 0.05$). The average self-efficacy score was 33.15 (SD = 7.74) out of a possible 40 points for participants. No direct relationships between group attendance or satisfaction and self-efficacy.
Ashbury et al.[49]	US	Observational (case-control)	367 women with breast cancer (175 intervention group, 192 controls), age >21 years	One-on-one, face-to-face, number and duration of sessions vary	No	Coping: FACT	No significant differences between program participants (Mean score 32.9, SD 7.2) and non-participants (Mean score 33.8, SD 7.5).
Chambers et al.[50]	Australia	Experimental (RCT)	189 heterosexual couples of men with prostate cancer (63 peer intervention group, 64 usual care group, 62 nurse intervention group), mean age of men 62.70 years	One-on-one couple, telephone, 12 months (6–8 sessions total)	Yes	Health behaviour: Utilisation of erectile dysfunction treatments (scale by Schover et al. 2002); therapeutic alliance: Working alliance inventory	At 12 months, men in the peer intervention ($z = 2.41$; $p = 0.016$) and nurse intervention ($z = 2.64$; $p = 0.008$) were more likely to use medical treatments for erectile dysfunction than men in the usual care arm. At 6 months, men in the nurse intervention reported greater therapeutic alliance on task and goal compared with men in the peer intervention ($p = 0.011$ and $p = 0.014$). Participants in the peer intervention were 3.14 times more likely to use medical treatment for ED than those in the usual care group ($z = 2.41$; $p = 0.016$) and those in the nurse intervention were 3.67 times more likely to use medical treatment than those in the usual care group ($z = 2.64$; $p = 0.008$).

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
Chan et al.[51]	China	Experimental (RCT)	76 women with breast cancer (16 social support self-help (SS) arm, 27 body-mind-spirit (BMS) arm, 16 supportive-expressive (SE) arm, 17 controls), mean age 48.67 years	Group, face-to-face, 5 weeks (3h per week)	No	Coping: Mini-MAC	After 8 months, a significant reduction in negative emotions among BMS group participants (M 14.09, $p = 0.04$, ES = 0.4) and a non-significant increase among the SS group (M 18.81). A significant increase in negative emotions among the SS group participants after 4 months (M 19.38, $p = 0.04$, ES = 0.39). Among BMS group participants, 96% indicated that the intervention had had some effect on them. Among SE and SS group participants, 88% and 63% felt some effects from the group.
Giese-Davis et al.[52]	US	Observational (cohort)	43 women with breast cancer (participants) and 39 female peer counsellors, median age 51.31 and 54.34 years respectively	One-on-one, face-to-face or by telephone or e-mail, 3-6 months (1-4 sessions per week)	Yes	Self-efficacy: CBI; emotional self-efficacy: SESES-C; knowledge: BCRQ to measure desire for cancer resource information	A significant improvement in cancer self-efficacy (CBI total score, $t\,(28) = 2.26$; $p = 0.03$) and desire for information on breast cancer resources among participants (BCRQ total score, $t\,(28) = -2.49$; $p = 0.02$) with moderate effect sizes: CBI total score 0.42; BCRQ total score −0.49. No significant effect on emotional self-efficacy.
Giese-Davis et al.[53]	US	Experimental (RCT)	104 women with breast cancer (sojourners) (52 intervention group, 52 controls) and 30 female peer counsellors (navigators), median age 53.7 and 53.6 years respectively	One-on-one, face-to-face or by telephone or e-mail, 12 months (weekly sessions)	Yes	Self-efficacy: CBI; knowledge: BCRQ	No significant effect on self-efficacy or BCRQ. However, the experience of the diagnosis as a traumatic stressor moderated outcomes: Those with a peer counsellor in the traumatic stressor group improved significantly more on cancer self-efficacy ($p = 0.02$ [Cohen's $d = 0.88$]) than controls.
Grande et al.[54]	UK	Observational (cross-	63 PSG participants with a cancer diagnosis (52 female, 10 male)	Group, face-to-face	No	Coping: Brief COPE	PSG participants were more likely to use adaptive coping

(Continues)

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
		sectional)	and 44 comparison sample (27 female, 17 male), median age 61 and 64.5 years respectively				strategies, including active coping ($p < 0.001$, Median PSG participants: 8.0 compared to non-participants: Median 6.0, OR: 1.68), planning ($p < 0.001$; Median: 8.0 compared to 5.0, OR: 1.46), reframing ($p < 0.001$; Median: 7.0 compared 5.0, OR: 1.58), acceptance ($p = 0.048$, Median: 8.0 compared to 7.0 in non-participants, OR: 1.31), emotional support seeking ($p = 0.031$, Median: 7.0 vs. 6.0, OR: 1.27) and instrumental support seeking ($p < 0.001$; Median: 6.0 vs. 3.0, OR: 1.50). An active approach to coping is associated with support group membership: OR 1.30 (1.05, 1.61), $p = 0.016$.
Haack et al.[55]	Germany	Observational (cross-sectional)	576 men with prostate cancer (441 PSG participants, 135 controls), mean age 71.9 years	Group, face-to-face, membership on average 6.50 years	No	Knowledge: Two self-developed knowledge tests (SHILD study); self-management skills: heiQ	PSG participants had greater knowledge about prostate cancer ($p < 0.001$; M PSG: 4.65 (1.74) versus non PSG M 3.87 (1.90)) and health care ($p = 0.020$; M PSG participants: 7.86 (2.50) versus non-PSG: M 7.27 (2.83)) and greater awareness of guidelines than non-participants ($p < 0.001$). Controlled for socioeconomic and clinical variables differences remained for detailed cancer knowledge (OR = 2.191, $p = 0.004$) but no significant difference on health care knowledge. The chance of having read a guideline is more than five times higher for PSG members (OR 5.089, $p < 0.001$) and almost 4 times higher for ever having heard about

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
							guidelines for PSG members (OR 3.723, $p < 0.001$). No essential group differences for heiQ dimensions. PSG participants revealed they received information on prostate cancer, ways for coping with prostate cancer, and ways to meet physicians.
Høybye et al.[56]	Denmark	Observational (cross-sectional)	100 online PSG users with a cancer diagnosis (90 female, 10 male) and 111 non-users of online PSG (94 female, 17 male), mean age 50 and 57 years respectively	Group, online, each for 3 months, participation at least once	No	Coping: Mini-MAC	Fatalism ($p = 0.0088$, M for users: 13 vs. non users: M 14) and cognitive avoidance ($p = 0.0009$, M: 9 vs. 10 (non-users)), both considered passive forms of coping, were significantly associated to non-participation in the online PSG. When adjusted for socioeconomic variables, the association only remained for cognitive avoidance ($p = 0.0282$).
Høybye et al.[57]	Denmark	Experimental (RCT)	794 cancer survivors (361 intervention group (84% female), 433 controls (90% female), mean age 53 and 55 years respectively	Group, online, 13 months, assessed at least twice	No	Coping: Mini-MAC	At 6 months follow-up, the effect of the intervention on coping and adjustment to cancer showed a transient difference, when the intervention group reported more anxious preoccupation ($p = 0.04$) and helplessness ($p = 0.002$). At 12 months no significant effects.
Huber et al.[58]	Germany	Observational (cross-sectional)	1641 prostate cancer patients (955 patients visiting face-to-face PSGs and 686 patients using online PSGs)	Group, online and face-to-face	Yes	Self-management skills: Control preferences scale on decision-making preferences; knowledge: Information received (evaluation questions); perceived control: Evaluation statement	Online PSG users preferred a more active role in the treatment decision-making process and changed their initial treatment decision more frequently than members of the face-to-face support groups ($p < 0.001$). Preferences for a passive role in the treatment decision-making

(Continues)

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
							process were rare among both groups (face-to-face 6% vs. 2% online PSG). Face-to-face PSG members received more information than online PSG users about treatments and health care providers. 55% of face-to-face PSG users and 41% ($p < 0.001$) of online PSG users felt more in control over what is happening to them through their participation.
Kühner et al.[59]	Germany	Observational (cross-sectional)	216 women with breast cancer (95 PSG participants, 121 non-participants), age 31–78 years	Group, face-to-face, participation at least twice, less than 2 years to more than 4 years	No	Knowledge: Newly developed self–administered questionnaire (Kühner et al.)	On 3 out of 4 knowledge subscales PSG participants scored significantly higher than non-participants (Cohen's d = 0.30-0.71). Effect size of differences of the overall knowledge score = 0.48. PSG participants had more extensive knowledge on disease, prevention and after-care in comparison to non-participants, even after controlling for education and age ($p < 0.001$, ß = 0.23), with education being a stronger predictor than PSG membership on total knowledge score. Duration of the disease and the length of PSG membership had no effect on levels of knowledge.
Lee et al.[60]	Korea	Experimental (RCT)	129 women with breast cancer (64 intervention group, 65 controls), age 20–64 years	One-on-one, face-to-face or by telephone, 6 weeks (4-6 sessions total)	Yes	Self-efficacy: SESSM-B; coping: Mini-MAC	Both intervention and controls improved self-efficacy over time. A significantly (p = 0.043) greater increase in self-efficacy for self-management of breast cancer among the intervention group (mean change of 4.6) in comparison to the controls (mean change 2.6). No statistical significant changes in mental adjustment between the two groups.

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
Mok[61]	China	Observational (cross-sectional)	449 PSG participants with a cancer diagnosis (297 female, 152 male), age 60% 30–59 years	Group, face-to-face	No	Coping: Agreement with statement about coping strategies (learnt in the group), knowledge: Agreement with statement about factual information obtained in the group	PSG participants reported to have learnt coping strategies in the group (94.2%), and to have obtained factual information in the group (86.6%).
Nápoles et al.[62]	US	Experimental (RCT)	150 women with breast cancer (76 intervention group, 74 controls), mean age 49 years	One-on-one, face-to-face or by telephone, 8 weeks (1 session per week)	No	Coping: Program evaluation survey including statements on how much the program helped the participants to cope; knowledge: Compañera tracking form and program evaluation survey	No differences on knowledge or in skill mastery between the intervention and control group. In program evaluation, 93% of the participants indicated the intervention helped them cope with breast cancer and reported improved knowledge.
Noeres et al.[63]	Germany	Observational (cross-sectional)	727 women with breast cancer (233 PSG participants, 233 non-participants, 391 PSG leaders)	Group, face-to-face	No	Knowledge: 55 item knowledge test developed by MHH	PSG participants demonstrated significantly more knowledge than non-participants ($p < 0.05$) and scored significantly higher than non-participants in knowledge domains of breast examination ($p < 0.05$) and lymphoedema ($p < 0.001$). Involvement in a PSG was most decisive for participants' knowledge, but other factors such as age, education, and medical history also had effects.
Nørskov et al.[64]	Denmark	Feasibility and pilot (experimental (non-RCT))	36 newly diagnosed leukaemia patients, 25 patient ambassadors (mean age: 54.5 years; 51.5 years)	One-on-one, (mostly) face-to-face, for 12 weeks	Yes	Self-efficacy: GSE; self-management skills: PAM	Statistically significant improvements from baseline to 12-week follow-up for self-management ($p = 0.021$) but not from 12 to 24 weeks follow up. No significant difference for self-efficacy.
Richter et al.[65]	Germany	Feasibility and pilot (experimental (pre-post))	19 patients (14 female, 5 male) with different cancer entities, mean age: 33.6 years	One-on-one, face-to-face, 3 months, every 2 weeks	Yes	Self-efficacy: SWE	Statistically significant improvements between t0 and t1 for self-efficacy ($t(17) = 2.48$, $p < 0.05$), with a moderate effect size (Cohens $d = 0.52$).

(Continues)

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
Salzer et al.[66]	US	Experimental (RCT)	78 women with breast cancer (51 intervention group, 27 controls), age ≥18 years	Group, online, 12 months	No	Self-efficacy: SESES-C	No statistically significant differences between the intervention and control group on self-efficacy.
Sautier et al.[67]	Germany	Observational (cohort analytic)	883 cancer patients (67 PSG participants, 816 non-participants), age 18–60 years	Group, face-to-face, mean frequency of 10.6 (SD = 3.6) sessions	No	Coping: DWI-GR	No significant differences in coping strategies among PSG participants and non-participants (t2). As a trend, group participants showed higher levels of active problem oriented coping ($p = 0.08$), active emotion-oriented coping, and less avoidance ($p = 0.06$) (t2). Undergoing an increased number of overall treatments, being unemployed, and having a higher active emotion-oriented coping style significantly predicted PSG participation ($p < 0.05$, OR 1.57) (t3).
Schreiber et al.[68]	Germany	Observational (cohort)	224 throat cancer patients (49 PSG participants, 175 non-participants), 30 female, 194 male), age 37–79 years	Group, face-to-face, regular participation	No	Health behaviour: Questionnaire to record health behaviour "Fragebogen zur Erfassung des Gesundheitsverhaltens"	The average monthly alcohol consumption among PSG participants was significantly lower than that of the non-participants ($p = 0{,}008$, 443 vs. 789 g/months). While 100% of PSG participants were non-smokers, 13% of non-participants smoked ($p = 0.02$). Amount of alcohol consumption is not a predictor for participating in a PSG ($p = 0{,}257$).
Seçkin[69]	US	Observational (cross-sectional)	255 female online PSG users with a cancer diagnosis, age 19–82 years	Group, online, frequently	No	Coping: PCA (2 items adapted from FACT)	Participation in online PSGs was found to increase positive coping affects significantly ($p < 0.001$, standardized $\beta = 0.221$), even stronger for patients >50 years. The association between

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
							characteristics of participation in online PSGs (e.g., frequency, number of groups) and the extent of perceived benefits was not supported.
Seçkin[70]	US	Observational (cross-sectional)	350 online PSG users with a cancer diagnosis (255 female, 95 male), age 19–83 years	Group, online	No	Coping: ECCS perceived benefits of electronic coping support, perceived coping ability: 3 items rating on 5-point Likert scale (2 items adapted from FACT)	A significant positive association between electronic coping support by PSGs and perceived coping ability with cancer ($p = 0.001$, $\chi2$ 21.93). Perceived ability to cope with cancer was also positively associated with health satisfaction ($p = 0.001$).
Sheppard et al.[71]	US	Observational (cohort)	15 women with breast cancer, age 36-66 years	One-on-one, face-to-face or by telephone, 2 sessions total	Yes	Knowledge: Statements about being better informed about breast cancer and treatment; self-management skills: Statements about improved involvement in decision making process	The participants found the intervention acceptable and reported better communication and decision-making skills. The majority of participants were more involved in their care, felt better informed, and prepared for treatment discussions after the intervention.
Shin and Park[72]	South Korea	Observational (cross-sectional)	264 women with breast cancer (137 PSG participants, 127 non-participants), age >20 years	Group, face-to-face, regular participation	No	Empowerment: CEQ	PSG participants (Mean score 144.75) showed a higher level of empowerment than non-participants (Mean score 137.97) ($p = 0.002$). For those who participated in PSGs, their empowerment and quality of life showed a high positive relationship ($p < 0.001$). Based on the analysis of the moderating effects on group participation, the interaction of empowerment and group participation status was statistically significant ($\beta = -0.26$, $p = 0.048$).

(Continues)

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
van Uden-Kraan et al.[73]	Netherlands	Observational (cross-sectional)	214 online PSG users with breast cancer (211 female, 3 male), age 25–72 years	Group, online, frequency of visits range from less than once a month up to more times a day	No	Empowerment: 67 developed items including questions on empowering processes and outcomes (partially based on the revised IPQ-R and on the Dutch version of the mastery scale)	Participants of online cancer PSGs experienced empowering outcomes to the strongest degree in 'being better informed' (Mean score 3.8 of 5), 'enhanced social well-being' (Mean score 3.4 of 4) and 'feeling more confident in the relationship with their physician' (M: 3.4). The empowering outcomes could only be predicted in a modest way by the processes that took place in the online PSG. Empowering processes taking place the most frequently in the PSGs are 'exchanging information' (M: 3.1 of 4) and 'finding recognition' (M: 2.9 of 4), even more prominently in the cancer group compared to other diagnoses.
Walshe et al.[74]	UK	Feasibility and pilot (experimental (RCT)	12 patients of different tumour entities (six patients in control group, mean age 69.6 and six patients in intervention group, mean age 64.8)	One-on one, either face-to-face or by telephone, ≤2 times per week for ≤12 weeks	Yes	Coping: Brief COPE	With regard to problem-focused coping, coping strategies decreased after 12 months for intervention group (M t0 13.83 (5.70), M t12 = 12 (7.65)) and remained the same for controls. For emotion-focused and dysfunctional coping an increase for controls and a decrease for the intervention group, however, it was not reported if those changes are significant.
Weber et al.[75]	US	Experimental (RCT)	30 men with prostate cancer (15 intervention group, 15 controls), age 48–67 years	One-on-one, face-to-face, 8 weeks (One session per week)	Yes	Self-efficacy: SICPA	At 8 weeks, self-efficacy significantly increased for men in the intervention group ($t = 2.2$, $p = 0.04$), and decreased for men in the control group. A high

TABLE 1 (Continued)

Reference	Country	Study design	Study population	Type and duration of peer support	Peer leader training	Empowerment dimension and instrument	Key findings
							correlation between self-efficacy and depression ($r = 0.65$, $p < 0.01$). The control group had significantly greater self-efficacy at baseline than the intervention group (M score = 319.5 and 290.3, respectively ($t = 2.5$, $p = 0.05$). The intervention effect was small for self-efficacy (ES = 0.20). The Median score in controls changed from 319.5 to 309.7, while the Median score for the intervention group changed pre-post from 290.3 to 314.9.
Weber et al.[76]	US	Experimental (RCT)	72 men with prostate cancer (37 intervention group, 35 controls), age ≥45 years	One-on-one, face-to-face, 8 weeks (1 session per week)	Yes	Self-efficacy: SICPA	By 8 weeks, self-efficacy significantly improved for men in the intervention group (Mean score at baseline = 305, and at 8 weeks = 329), but not for men in the control group (Mean score at baseline = 309, and at 8 weeks = 300). The intervention significantly accounted for changes in physical role functioning, mental health, and social function. Age, education, and self-efficacy had significant interaction effects and increased the effects of the intervention on outcomes.

Abbreviations: BCRQ, breast cancer resources questionnaire; CBI, cancer behavior inventory; CEQ, cancer empowerment questionnaire; COPE, coping orientation to problems experienced; DWI-GR, dealing with illness inventory-German revised; ECCS, electronic cancer coping scale; GSE, General Self-Efficacy Scale; MHH, Hannover Medical School; PAM, Patient Activation Measure; PCA, positive coping affect; PSG, peer support groups; RCT, randomised controlled trial; SESSM-B, self-efficacy scale for self-management of breast cancer; SESES-C, Stanford emotional self-efficacy scale–cancer; SICPA, Stanford inventory of cancer patient adjustment; SWE, Selbstwirksamkeitserwartung.

Control

One observational study assessed perceived control in a sample of prostate cancer patients and found that 55% of face-to-face PSG users and 41% of online PSG users felt more in control over what was happening to them through their participation ($p < 0.001$).[58]

Self-efficacy

Three RCTs found a statistically significant positive association for self-efficacy in prostate or breast cancer patients and participation in 6–8 weeks dyadic peer interventions.[60,75,76] All peers received training prior to the interventions. After the six week intervention, self-efficacy increased for both intervention and usual care control groups of breast cancer patients, but significantly greater within the intervention group ($p = 0.043$).[60] In both studies by Weber et al., self-efficacy increased after eight weeks ($p = 0.04$) among the prostate cancer patients in the intervention group but not in the control group.[75,76] The effect sizes were small.

Two experimental feasibility studies with sample sizes smaller than 40 patients assessed effects of dyadic peer support with sessions over a period of three months on self-efficacy among cancer patients.[64,65] The peer-to-peer contacts here were mainly face-to-face. In both studies, the peer consultants received basic training prior to the intervention. One of them found a statistically significant improvement between t0 and t1 for self-efficacy ($p < 0.05$) with a medium effect size of 0.52 (Cohens d).[65]

One US cohort study examined the association between attendance of dyadic peer support and self-efficacy in breast cancer patients.[52] The peer leaders received training before they provided their support face-to-face, by telephone or via e-mail. A significant improvement in cancer self-efficacy to cope with treatment and side effects among participants was observed (CBI total score 2.26; $p = 0.03$, with an effect size of 0.42 on the CBI total score), but not in emotional self-efficacy.

3.3.3 | Interactional component

Thirteen studies examined outcomes of the interactional component of PE, of which 10 found positive effects consisting of small to medium effect sizes and perceived improvements.[52,55,58,59,61–64,71] Three studies did not find any associations between participating in peer support and interactional empowerment.[53,55,62] Selected findings are described in the following.

Knowledge

Nine studies examined the association between peer support and cancer-related knowledge, of which four used knowledge tests[55,59,62,63] and five assessed perceived improvement in knowledge through the PSGs.[52,53,58,61,71] Two RCTs carried out in the US did not find differences in knowledge between breast cancer patients in the intervention and in the control groups.[53,62] Both interventions were dyadic and provided support face-to-face, or by telephone over two to 12 months. Three observational studies reported a perceived increase in knowledge through peer group participation.[58,61,71]

Four further observational studies measured knowledge about the disease including cancer treatments, after-care and prevention through objective knowledge tests.[52,55,59,63] They revealed weak to moderate positive associations between cancer knowledge and participation in peer support interventions which were mainly held face-to-face.[52,55,59,63] According to three studies, participants of face-to-face cancer PSGs demonstrated significantly greater knowledge about cancer than non-participants.[55,59,63] Some subscales showed rather large effects, as the chance of having read a guideline was more than five times higher for group members (OR 5.089; $p < 0.001$) and nearly four times higher for ever having heard about guidelines (OR 3.723; $p < 0.001$) compared to non-members. The effect size for knowledge about long-term effects such as lymphoedema was 0.71 (Cohens d).[59] Those differences remained significant after controlling for socioeconomic and clinical variables. The fourth study used the BCRQ to measure desire for cancer resource information in women with breast cancer and observed a moderate effect (Cohen's $d = -0.49$) of peer support on knowledge and reported significant improvement among participants of a dyadic support intervention (BCRQ total score −2.49; $p = 0.02$).[52]

Self-management skills

In a non-randomised trial with 36 newly diagnosed leukaemia patients, Nørskov et al. found statistically significant improvements in patient activation levels ($p = 0.021$) in the follow-up 12 weeks after baseline. No further improvements were found between this follow-up and a second follow-up assessment 24 weeks after baseline.[64]

A cross-sectional study from Germany demonstrated higher scores for long-time group members with regard to health care navigation skills (OR 1.787, $p = 0.004$) but could not find significant group differences in self-management skills between peer support participants and non-participants.[55,77] Sheppard et al. reported that more than 60% of the breast cancer patients participating in dyadic peer support sessions felt at least somewhat more involved in their treatment decision-making process after the intervention.[71] A cross-sectional study comparing participants of face-to-face to online PSGs found that preferences for a passive role in the treatment decision-making process were rare among both groups (6% and 2%) and that online PSG users preferred a more active role than members of the face-to-face PSGs ($p < 0.001$).[58]

3.3.4 | Behavioural component

Fourteen studies were found that examined the behavioural component of PE and participation in peer support. The majority of these[50,54,56,61,62,68–70] found positive associations with small to medium effect sizes and perceived benefits. Four did not find any associations[49,60,67,74] and two found transient negative effects,[51,57] which are presented below.

Active coping

Among seven observational studies, five reported a positive association between coping and participation in PSGs led by non-trained peers,[54,56,61,69,70] while two did not find any significant differences among PSG participants and non-participants.[49,67] Three studies found a small but significant positive association between PSG participation and positive active coping styles.[54,56,69] To illustrate, participation in online PSGs was found to increase positive coping significantly after being a member for two years on average ($p < 0.001$, $\beta = 0.221$).[69] When compared to non-participants and adjusted for socioeconomic variables, cognitive avoidance was significantly associated to non-participation ($p = 0.028$).[56] Support group participants were 1.5 times more likely to seek instrumental support than non-participants.[54] Seçkin observed a significant positive association between online peer support and perceived coping ability with cancer ($p = 0.001$) and that perceived ability to cope with cancer was positively associated with health satisfaction ($p = 0.001$).[70] Additionally, PSG participants of a cross-sectional study reported to have learnt coping strategies through the group.[61]

Among five experimental studies, one study reported improved coping for participants of a body-mind-spirit group led by a skilled social worker ($p = 0.04$; ES = 0.4), but not for participants of the PSG intervention.[51] In addition, two RCTs showed a temporary deterioration in coping skills among PSG participants compared to non-participants: Chan et al. reported a transient significant increase in negative emotions after four months ($p = 0.04$; ES = 0.39),[51] and Høybye et al. demonstrated a transient significant increase in anxious preoccupation ($p = 0.04$) and helplessness ($p = 0.002$) at six months follow-up among the intervention group.[57] Lastly, in a pilot RCT, the authors found a decrease in problem-focused coping for participants of the dyadic peer intervention and an increase in emotion-focused and dysfunctional coping after 12 months, but did not indicate whether these effects were significant.[74]

Health behaviour

Two studies focused on the behavioural component of PE. A three-arm RCT investigated effects of a peer support intervention versus nurse counselling for couples on utilisation of erectile dysfunction treatments compared to usual care.[50] The interventions were carried out via telephone and were found to have significant effects on prostate cancer patients' health behaviour after 12 months. Logistic regression analyses revealed an improvement among both intervention groups. Men in the peer intervention were 3.14 times more likely to use medical treatment for erectile dysfunction than those in the usual care arm ($z = 2.41$; $p = 0.016$), while in the nurse-led intervention, patients were 3.67 times more likely to use medical treatment ($z = 2.64$; $p = 0.008$).

In a German observational study, the authors investigated the association between PSG participation and smoking and alcohol consumption in 224 throat cancer patients.[68] The average monthly alcohol consumption among PSG participants was significantly lower than that of the non-participants ($p = 0.008$), and while all group participants were non-smokers, 13% of non-participants smoked ($p = 0.02$). A logistic regression showed that the amount of alcohol consumption was not a predictor of participation in a PSG.

4 | DISCUSSION

To our knowledge, this is the first systematic review to explore associations between participation in peer support and PE in cancer patients in quantitative studies. We identified 29 relevant papers and found a high heterogeneity in study designs, study quality, peer support intervention type and mode of delivery, and the participants. The majority of these studies were observational and most studies showed moderate study quality. Relevant outcomes were identified for all three components of PE, consisting of empowerment, control, self-management skills, self-efficacy, active coping, knowledge and health behaviour. Representing outcomes in the three components of PE, coping, self-efficacy and knowledge were most frequently assessed in the studies, and accounted for most of the significant findings, indicating that these variables are more established and researched than the others included in our search terms.

In total, two thirds of the findings ($n = 27$ of 39) reported positive significant associations between peer support and PE, with small to moderate effect sizes[52,54–56,58–61,63–65,68–70,72,75,76] and perceived benefits. Less than a third did not find any associations,[49,52,55,60,62,66,67] and only three negative associations were observed.[51,57,74] Notably, these negative effects were either transient[51,57] or even stronger in the control group,[74] suggesting that coping would deteriorate less with peer support. Consequently, the findings indicate that participating in peer support can be seen as beneficial overall and peer support does appear to make a difference with regard to empowerment, albeit a rather small one. These findings extend those of previous reviews which also reported positive but limited evidence for beneficial effects on empowerment and no harm of participating in PSGs.[80–82]

Concerning our first preliminary consideration we found positive results in six out of eight experimental studies included in this review that provided peer leaders with training in communication skills, leadership or cancer terminology.[50,60,64,65,75,76] Two out of the three experimental studies that reported small and temporary negative associations between peer support and coping had untrained peer leaders.[51,57] In several observational studies significant results were found, although none of the peer leaders received training. These findings may suggest that it is not only the peer leader training that is important, but also the many years of experience that the leaders have gained from their own cancer history and leading a group as well as the lasting relationships formed between members and leaders. This is also supported by our finding that larger effects were particularly visible in long-existing groups than in groups formed as part of a research project.

Six of the 10 studies assessing the intrapersonal component of PE found positive associations with small to medium effects even through short-term peer support interventions, supporting our second consideration of Zimmerman's theory insofar that empowerment in this component could form early on. Similarly, effect sizes of peer support participation on the interactional component of PE, which mainly consisted of knowledge, ranged from small to medium. In some of the reviewed studies the vast majority of participants reported self-perceived increase of information through the peer support intervention.[55,58,61,62,71] Further, exchange of information was named in one study as one of the main empowering processes that took place in the PSG.[73] Those findings demonstrate that, in fact, informational support is a key empowerment goal of PSGs, and the positive association of peer support participation and knowledge overall demonstrates that knowledge transfer does take place in PSGs, even in short term interventions.

Surprisingly, with regard to active coping, positive effects were of a similar size and amount compared to those on the intrapersonal component, even in groups with short periods of participation. Those findings contrast with our consideration that improvements in the behavioural component of PE such as coping in cancer would only be achieved after long-term participation in a PSG. Instead, the findings indicate that strengthening patients' coping skills are core goals of cancer PSGs that are indeed accomplished and are in line with results of previous qualitative studies that similarly stressed benefits of participating in peer support for coping ability.[28,83,84]

Regarding the third preliminary consideration guiding this review concerning the mode of delivery of peer support, we found mixed results. Positive effects on self-efficacy,[52,65,75,76] control[58] and knowledge[52,55,58,59,63] were observed most frequently in relation to face-to-face peer support interventions as it may be easier to tailor the needs of the participants. Ihrig et al. however, demonstrated that prostate cancer patients gained informational support through online peer support as well.[40] Positive outcomes in coping seem to be achieved particularly well through online interventions in group settings[54,69,70] which was also demonstrated in a previous study.[85] This might be due to participants having quick and easy access to the online group anytime to seek support for urgent acute matters. With regard to self-management skills, benefits were reported in both face-to-face and online support interventions, but were even higher for online PSG users when compared directly to face-to-face PSGs.[58] Our findings therefore contradict a previous systematic review, which found inconsistent evidence for the efficacy of online peer support interventions for cancer patients.[37] Consequently, digital solutions could be seen as beneficial supplements or even an equally beneficial alternative. Their relevance is likely to increase, particularly in the light of the Covid-19 pandemic.

Additionally, although dyadic peer support is more intensive than group support, the form of peer support provided did not seem to have an impact on empowerment in the included studies. Thus, our findings support those of previous reviews, which showed significant effects of PSG participation but did not find clear commonalities among different forms of peer support overall.[36,80]

Only two studies measured empowerment explicitly[72,73] and an additional seven[56,58,61,63,68–70] mentioned empowerment as being related to their findings, demonstrating the dearth of research explicitly focussing on empowerment and PSGs. While there is a need for further research on empowerment and participation in PSGs, this research need might not necessarily be supported by PSG representatives. Cancer survivors have been engaged in and promoting peer support for decades and may therefore not see a need for research evidence to prove an effectiveness of PSGs, which they perceive as obvious.

The large amount of perceived benefits stressed across studies reflects the observation described by Kieffer, that individuals engaged in grassroots organisations view empowerment not necessarily as 'having more power' but at least as 'feeling more powerful'.[16](p.32) It seems that subjective, experience-based assessments, respectively, produce more positive results than standardised health outcome measures, which begs the question of whether study designs and measures are adequate with respect to the needs, desires and interests of those concerned.[86,87] Although the impact of PSGs on knowledge was evident in standardised measures of cancer knowledge, the complex and individual empowerment support that takes place in PSGs may be difficult to capture through standardised instruments. Therefore, the impact of PSGs on knowledge may be underestimated in our findings, highlighting the value of conducting qualitative research on this topic.

Nonetheless, these methodological challenges should not be taken as a reason for omitting research on peer support. However, we believe that patient participation and involvement[88–90] are essential in future research on this topic, not only in the beginning of a study (e.g. in recruiting patients), but throughout the whole research project and the dissemination of its results, as well as in the development of the interventions themselves, in accordance with the ladder of participation.[91,92] An engaged research approach is necessary to find and to shape the relevant research questions, to help health care professionals to understand better, and to improve care and patient centeredness.[93] Further, it is even more important to better align different expectations and incorporate the expertise that both health care professionals and engaged patients and their relatives have. 'Nothing about us without us' has never lost its relevance.[94] In the era of patient-centeredness, it might be more relevant than ever.

4.1 | Study limitations

It is important to note that there are several limitations in the strength of the evidence presented in this review, foremost because of heterogeneity in the quality of the included studies. More than a third of the articles that reported significant results were rated as having a poor study quality, undermining the credibility of the evidence.[54,58,59,63,69,70,72] Studies with non-significant findings that were included in the review all had a higher quality rating, indicating that more robust research is less likely to have significant findings. These results are consistent with other systematic reviews, which found low quality of reporting in many trials, so results should be interpreted with caution.[36] Further, as the observational studies cannot rule out that PSG participants differ from non-participants with regard to baseline levels of empowerment, we could not determine if PSG participants are more empowered per se. Thus, adequately powered RCTs with long-term follow-ups are needed.

The exclusion of qualitative research represents another limitation of this review. Qualitative studies provide meaningful insight on the benefits of participating in PSGs with regard to empowerment. However, they address empowering processes rather than empowerment outcomes. The large amount of relevant qualitative studies identified in our database searches are worth to be explored in a future systematic review of qualitative studies to improve our understanding of the processes underlying the changes in empowerment outcomes identified in the present review.

In addition, only peer reviewed journal articles published in English or German were considered. Additional 'grey literature' may contain further relevant and useful information on the research question. Thus, due to publication bias the positive results may have been overestimated. We have approached empowerment using Zimmerman's definition of PE, hence, other definitions of empowerment may have resulted in different findings. A meta-analytic approach may have provided further insight into the nature of the findings. However, the heterogeneity of the study quality, study designs with diverse intervention types, length, instruments, outcomes and empowerment dimensions precluded this.

4.2 | Clinical implications and recommendations

First, since the majority of studies reported that PSGs improve patients' empowerment, which, among other benefits, may result in better therapeutic adherence and patient-provider-communication, it seems desirable to systematically integrate PSGs in hospitals and the oncological care system as a whole. For the integration of PSGs in cancer care and to provide patients access to PSGs from an early stage, a close collaboration between clinicians and PSGs would be fruitful. The approved concept of Self-Help Friendliness[86,87] as a patient centred approach to implement patient involvement in health care may work as a suitable measure for improving cooperation between health care professionals and PSGs.

Second, especially in the light of the current COVID-19 pandemic resulting in many face-to-face group meetings being cancelled, online PSG interventions are an appropriate alternative. PSGs could therefore be encouraged to maintain or further develop their online services. Compared to face-to-face-meetings and with regard to participants' empowerment, these can be seen as equally beneficial. Delivering online peer support offers specific advantages such as wider reach through accessibility, enabling constant availability, more frequent and flexible participation, low costs as well as a degree of anonymity if data protection is granted. However, they may not create the same emotional closeness that face-to-face groups provide. This should be examined further in future research.

5 | CONCLUSIONS

Although the identified studies had methodological flaws and did not cover all dimensions of PE, we found that participation in cancer peer support had a small to moderate impact on all three components of empowerment. Further, the findings suggest that peer support is beneficial for empowering cancer patients regardless of mode, duration and format of the interventions. There is a need for studies with long-term follow-up and larger sample sizes, combining self-reported subjective and objective measures.

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CONFLICT OF INTEREST

The authors report no conflict of interest.

AUTHOR CONTRIBUTION

All authors contributed to and approved the final manuscript.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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Supplementary information

TABLE S1: Search terms and results of databases searched

Databases Searched	**Search Terms Used**	**Number of Results**
PubMed	(cancer OR neoplasm OR tumor OR tumour OR oncology OR oncologic) AND ("self help group" OR "self help organization" OR "self help organisation" OR "collective self help" OR "mutual aid" OR "mutual help" OR "mutual support" OR "support group" OR "peer support" OR "peer counseling" OR "patient organization" OR "patient organisation") AND (control OR "health literacy" OR knowledge OR "self management" OR "self efficacy" OR "health promotion" OR "health behavior" OR "health behaviour" OR prevention OR empowerment OR coping OR competency OR competencies OR competence OR skill OR skills OR ability OR abilities OR "patient participation" OR "patient involvement")	1061
Web of Science (core collection)	(cancer OR neoplasm OR tumor OR tumour OR oncology OR oncologic) AND ("self help group" OR "self help organization" OR "self help organisation" OR "collective self help" OR "mutual aid" OR "mutual help" OR "mutual support" OR "support group" OR "peer support" OR "peer counseling" OR "patient organization" OR "patient organisation") AND (control OR "health literacy" OR knowledge OR "self management" OR "self efficacy" OR "health promotion" OR "health behavior" OR "health behaviour" OR prevention OR empowerment OR coping OR competency OR competencies OR competence OR skill OR skills OR ability OR abilities OR "patient participation" OR "patient involvement")	1220
CINAHL	(cancer OR neoplasm OR tumor OR tumour OR oncology OR oncologic) AND ("self help group" OR "self help organization" OR "self help organisation" OR "collective self help" OR "mutual aid" OR "mutual help" OR "mutual support" OR "support group" OR "peer support" OR "peer counseling" OR "patient organization" OR "patient organisation") AND (control OR "health literacy" OR knowledge OR "self management" OR "self efficacy" OR "health promotion" OR "health behavior" OR "health behaviour" OR prevention OR empowerment OR coping OR competency OR competencies OR competence OR skill OR skills OR ability OR abilities OR "patient participation" OR "patient involvement")	474
Cochrane (Trials)	(cancer OR neoplasm OR tumor OR tumour OR oncology OR oncologic) AND ("self help group" OR "self help organization" OR "self help organisation" OR "collective self help" OR "mutual aid" OR "mutual help" OR "mutual support" OR "support group" OR "peer support" OR "peer counseling" OR "patient organization" OR "patient organisation")	582

	AND (control OR "health literacy" OR knowledge OR "self management" OR "self efficacy" OR "health promotion" OR "health behavior" OR "health behaviour" OR prevention OR empowerment OR coping OR competency OR competencies OR competence OR skill OR skills OR ability OR abilities OR "patient participation" OR "patient involvement")	
Ovid Medline (PsycINFO, PSYNDEX)	(cancer OR neoplasm OR tumor OR tumour OR oncology OR oncologic) AND ("self help group" OR "self help organization" OR "self help organisation" OR "collective self help" OR "mutual aid" OR "mutual help" OR "mutual support" OR "support group" OR "peer support" OR "peer counseling" OR "patient organization" OR "patient organisation") AND (control OR "health literacy" OR knowledge OR "self management" OR "self efficacy" OR "health promotion" OR "health behavior" OR "health behaviour" OR prevention OR empowerment OR coping OR competency OR competencies OR competence OR skill OR skills OR ability OR abilities OR "patient participation" OR "patient involvement")	274 (PsycINFO: 265, PSYNDEX: 9)

Table S2: Effective Public Health Practice Project Quality Assessment of included studies

Study	Selection bias	Study design	Confounders	Blinding	Data collection	Withdrawals and drop-outs	Overall rating
Antle and Collins (2009)	Weak	Moderate	Strong	Moderate	Strong	Strong	Moderate
Ashbury et al. (1998)	Moderate	Moderate	Strong	Moderate	Strong	N/A	Strong
Chambers et al. (2015)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Chan et al. (2006)	Moderate	Strong	Strong	Moderate	Strong	Strong	Strong
Giese-Davis et al. (2006)	Moderate	Moderate	Strong	Moderate	Strong	Moderate	Strong
Giese-Davis et al. (2016)	Moderate	Strong	Strong	Moderate	Strong	Strong	Strong
Grande et al. (2006)	Weak	Weak	Strong	Moderate	Strong	N/A	Weak
Haack et al. (2018)	Moderate	Weak	Strong	Moderate	Strong	N/A	Moderate
Høybye et al. (2010)	Moderate	Weak	Strong	Moderate	Strong	N/A	Moderate
Høybye et al. (2010a)	Moderate	Strong	Strong	Moderate	Strong	Moderate	Strong
Huber et al. (2018)	Weak	Weak	Weak	Moderate	Strong	N/A	Weak
Kühner et al. (2006)	Moderate	Weak	Strong	Moderate	Weak	N/A	Weak
Lee et al. (2013)	Moderate	Strong	Strong	Moderate	Strong	Moderate	Strong
Mok (2001)	Moderate	Weak	Strong	Moderate	Weak	N/A	Weak
Nápoles et al. (2018)	Moderate	Strong	Strong	Moderate	Weak	Strong	Moderate
Noeres et al. (2011)	Moderate	Weak	Weak	Moderate	Strong	N/A	Weak
Nørskov et al. (2020)	Moderate	Strong	Strong	Moderate	Strong	Weak	Moderate
Richter et al. (2020)	Weak	Moderate	Strong	Moderate	Strong	Strong	Moderate
Salzer et al. (2010)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Sautier et al. (2014)	Moderate	Moderate	Strong	Moderate	Strong	Moderate	Strong
Schreiber et al. (2013)	Moderate	Moderate	Weak	Moderate	Strong	Moderate	Moderate
Seçkin (2011)	Weak	Weak	Strong	Moderate	Strong	N/A	Weak
Seçkin (2013)	Weak	Weak	Strong	Moderate	Strong	N/A	Weak
Sheppard et al. (2008)	Moderate	Moderate	Strong	Moderate	Strong	Weak	Moderate
Shin and Park (2017)	Weak	Weak	Strong	Moderate	Strong	N/A	Weak
van Uden-Kraan et al. (2009)	Weak	Weak	Strong	Moderate	Strong	N/A	Weak

Walshe et al. (2020)	Weak	Strong	Strong	Strong	Strong	Moderate	Moderate
Weber et al. (2004)	Moderate	Strong	Strong	Moderate	Strong	Strong	Strong
Weber et al. (2007)	Moderate	Strong	Strong	Moderate	Strong	Strong	Strong

N/A, not applicable

6. Publication 2

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ORIGINAL PAPER

Development and psychometric properties of a brief generic cancer knowledge scale for patients (BCKS-10)

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Abstract

Purpose This study aims to introduce the development and psychometric properties of a brief generic cancer knowledge scale for patients (BCKS-10) that includes different elements of knowledge and skills (terminology, diagnosis, treatment, prevention, and numeracy). Although cancer knowledge is a central dimension of cancer literacy, most previous studies either investigated cancer knowledge among the general population, or among patients with a specific cancer diagnosis.

Methods Qualitative interviews ($n = 11$) and a quantitative survey ($n = 267$) among peer support group leaders were conducted to further develop the BCKS-10 after literature screening. $n = 500$ patients with cancer were recruited across Germany between October 2020 and February 2021. Construct validity, item discrimination and reliability were tested.

Results ANOVA revealed no significant differences of the knowledge score between various cancer sites, a significant positive association with education, and a negative association with migration background by trend supporting construct validity. In terms of item discrimination, the corrected item-total correlation of 8 out of 10 items were above the threshold of 0.3. Cronbach's alpha of about 0.68 revealed an acceptable internal consistency as the tool is brief and consists of different dimensions.

Conclusion Overall, the findings show that the BCKS-10 is a suitable tool to briefly assess cancer knowledge among patients independent of cancer site. However, further surveys have to be conducted to validate the psychometric properties and enhance the BCKS-10.

Keywords Cancer knowledge · Health literacy · Psychometrics · Patient education

Introduction

During the past decades, health literacy became a highly relevant factor of health management and an important topic of patient-centred care [1, 2]. Reviewing the various definitions and conceptual models of health literacy, knowledge is an essential dimension when examining health literacy [3]. An overview of existing measurement tools of health literacy found a trend towards a mixed measurement including self-perceived and objective tests, as the assessment of objective knowledge widens the possibility to address multiple skills (e.g. numeracy) [4]. However, the study reports psychometric weaknesses of current tools and highlights the need to develop further instruments. These findings also hold true for cancer literacy. In terms of complex chronic diseases like cancer and a more and more challenging navigation within the health care systems, cancer knowledge is a substantial component of patients' health, well-being and patient safety [5]. One study showed that health literacy, assessed by an objective knowledge test, is an independent predictor of cancer patients' hospitalizations in the first five years after their diagnosis [6]. Moreover, a current overview summarised that lower health literacy was associated with greater difficulties to understand and process cancer related information as well as poorer quality of life and poorer experience of care [7]. Following a systematic review from 2015 [8], there is a limited number of cancer literacy and/or cancer knowledge measurement tools, a lack of reporting psychometric properties and no established inventory to date. Further, numeracy is a substantial dimension of health literacy [1, 9]. Numbers and numeric-based concepts are highly relevant regarding health-related communication and decision making. In

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terms of cancer, the assessment of risks, odds and prognoses as wells as the understanding of drug leaflets and further health information are essential skills for patients. Previous studies that assessed cancer knowledge either investigated knowledge among the general population or among patients with a specific cancer diagnosis [10–15]. Surveys among the general population are also relevant (e.g. in terms of early detection). However, cancer patients need particular knowledge about treatment options, medical terms and definitions [5]. Furthermore, many studies defined knowledge solely relating to symptom interpretation and not as a multidimensional construct [16]. Only one study examined generic cancer knowledge among patients regardless of cancer site, reporting good psychometric properties and limited cancer knowledge in about 18% [17]. The rationale for BCKS-10 was to develop a cancer knowledge scale, which (1) is brief, (2) refers to cancer patients (and not to the general population/laypersons), (3) is applicable for various cancer diagnoses, and (4) includes several dimensions of knowledge (i.e. terminology, diagnosis, treatment, prevention, legal matters and numeracy). The aim of this paper is to introduce the development of the BCKS-10, its components and psychometric properties.

Methods

Instrument development and design

There were three phases to the development process of the BCKS-10: (1) screening literature for existing instruments, (2) qualitative expert interviews with cancer peer support group leaders, (3) quantitative survey of cancer peer support group leaders. Out of the existing literature, particularly the Numeracy Understanding in Medicine Instrument (NUMi) ($n = 1000$ (general population); Cronbach's $\alpha = 0.86$) [9], and the Test for Ability to Interpret Medical Information (TAIMI) ($n = 6047$ (general population); Cronbach's $\alpha = 0.36$–0.51) [18] were considered for further development of the BCKS-10 in terms of numeracy skills. To include the patients' perspective and needs into the development process, expert interviews ($n = 11$) and a survey ($n = 267$), both among cancer peer group leaders, were conducted. Both investigations were focused on the patients' health care situation as well as current gaps and requirements of cancer knowledge, comprehension and communication. The BCKS-10 is part of a 13 items scale. The items 11–13, however, are nation-specific as they refer to knowledge about legal matters and administration in Germany, and thus, they are not appropriate for international use. Although data from the interviews and survey showed that this topic is relevant, these items were excluded from the international version due to large differences in the health care systems and legal conditions (i.e. items concerning the beginning of rehabilitation, the application of a disabled person's card, and the duration of sick pay). Therefore, only the first 10 items were included in the present analysis. Based on the experts' interviews and survey data, eight items regarding terminology, diagnosis, treatment and prevention were originally developed. As the interpretation of medical data was also mentioned as important for patients, two numeracy and data interpretation items (no. 3 and 5 of the BCKS-10) were adopted from the original NUMi (question no. 10) and TAIMI scale (question no. 5) and included in the instrument [9, 18] (see Online Resource for the complete instrument). The score ranges from 0 to 10 and a higher score indicates a higher cancer knowledge. A short pre-test ($n = 13$) was conducted in two hospitals in Hamburg. The results were assessed in collaboration with experts and clinicians and were rated as sufficient.

Participants and setting

For recruitment, a multi-channel approach was applied to reach a large variety of cancer patients in different phases of treatment and areas of health care. Throughout Germany, the following organisations, facilities and institutes were contacted: hospitals with an oncological ward, rehabilitation clinics for cancer patients, cancer counselling centres, cancer societies of the federal states, comprehensive cancer centres, oncological practices as well as self-help organisations and self-help groups (via snowball sampling). Additionally, the study was advertised via public relations. Eligible participants were adults ($18 \geq$ years) and diagnosed with cancer regardless of cancer site, stage or time of the diagnosis. The study participation was voluntary and anonymous. Patients could participate online or alternatively via paper–pencil questionnaire. The study is part of the research project "Health literacy, self-help activities and health care experience of people with cancer'' (gesa-K). The BCKS-10 is part of a larger multidimensional comprehensive survey that, in addition to the BCKS-10, includes tools to assess health status, health care experiences, health-related quality of life, coping, self-help activity and sociodemographic characteristics (www.uke.de/gesa-k). The survey commenced in October 2020, and the first 500 respondents that fully completed the BCKS-10 questionnaire were included in the psychometric analysis.

Analyses

The psychometric properties of the BCKS-10 were tested in various ways. Based on previous research, construct validity was assessed by testing assumptions about expected differences in knowledge scores among the sample [19]. A positive correlation of the BCKS-10 score with the educational level (years of schooling) of the respondents, and a negative correlation with the migration status (no = 0; yes = 1) were assumed (a person has a migration background, if he/she or one of his/her parents were born abroad) [9, 16, 17]. Furthermore, no significant differences regarding the individual cancer site were presumed as the tool was aimed to be generic and not to be focused on a specific cancer site. Analyses of variance (ANOVA) were conducted to test these conditions. For the latter, the five most frequent cancer sites in the sample were introduced in the analyses.

To evaluate reliability, the internal consistency was measured using Cronbach's alpha. A common threshold for alpha is 0.7 [19], but should not exceed 0.9 as it indicates unnecessary redundancy [20]. For further item analysis, an item difficulty index ranging from 0 to 1 (high difficulty scores indicate a greater proportion of the sample who answered the question correctly), and the corrected item-total correlation (range from 0 to 1) to show the coherence between an item and all other items in the scale. Adjusted item-total correlations below 0.3 are not desirable [19]. Additionally, the mean score of the BCKS-10, standard deviation, median, skewness, kurtosis and Shapiro–Wilk-test on normality of distributions were calculated. All analyses were carried out using the Statistical Package for the Social Sciences (SPSS) 26 [21].

Results

The sample characteristics are shown in Table 1. About 55% of the respondents were male, the mean age was about 63 years, ranging from 20 to 86 years. More than half of the respondents had a high or very high educational level and 8% a migration background. On average, six years passed since the time of the first cancer diagnosis. All UICC tumour stages (0–4) were represented. The five most prevalent cancer sites among the sample were prostate, breast, bladder, colorectum, and the subgroup including leukaemia, lymphoma and myeloma. Due to the recruitment processes nearly 62% of the patients previously or currently participated in peer support groups at the time of recruitment.

Figure 1 and Table 2 provide more information about the distribution and characteristics of the BCKS-10. The BCKS-10 score ranges from 0 (very low cancer knowledge) to 10 (very high cancer knowledge). The mean score was 7.53 (standard deviation 1.98). The distribution is left-skewed, however, the Shapiro–Wilk-test revealed a normal distribution.

Three univariate ANOVA were calculated to test conditions for construct validity (Table 3). The mean scores for the BCKS-10 did not differ between patients of different cancer sites ($p = 0.288$). Furthermore, the analyses revealed highly significant differences between the educational groups indicating a clear gradient in favour of higher educated patients ($p \leq 0.001$). In terms of migration status, the ANOVA did not show a significant difference ($p = 0.193$) but a trend towards a higher score among people without migration background. Multivariate analyses that were adjusted for education did not change significantly the results. Analyses of item difficulty and item discrimination (both with an overall range from 0 to 1) are presented in Table 4. The scores for item difficulty range from 0.432 to 0.990, the item discrimination varies from 0.244 to 0.414. In terms of reliability, the calculation of internal consistency showed a Cronbach's alpha value of

Table 1 Sample characteristics and distribution of variables ($n = 500$): n (%) or mean ± standard deviation

Sex *(0)*	
Female	228 (45.6)
Male	272 (54.4)
Age (years) *(3)*	62.9 ± 12.1
Education (years) *(0)*	
Low (≤ 9)	49 (9.8)
Middle (10)	133 (26.6)
High (12–13)	88 (17.6)
Very high (> 13/university degree)	230 (46.0)
Migration background *(3)*	
Yes	41 (8.2)
No	456 (91.2)
Time since diagnosis (years) (0)	5.9 ± 6.2
Tumour stage (UICC) *(11)*	
0	14 (2.8)
I	50 (10.0)
II	77 (15.4)
III	105 (21.0)
IV	36 (7.2)
Unknown	207 (41.4)
Cancer site *(0)*	
Prostate	139 (27.4)
Breast	125 (25.0)
Bladder	65 (13.0)
Colorectum	37 (7.4)
Leukaemia, lymphoma and myeloma	37 (7.4)
Head and neck	22 (4.4)
Thyroid	16 (3.2)
Ovary and peritoneum	11 (2.2)
Lung	8 (1.6)
Skin melanoma	7 (1.4)
Other	20 (4.0)
Multiple entities	13 (2.6)
Participation in peer support groups *(0)*	
No	191 (38.2)
Yes (current or former)	309 (61.8)

Number of missing data in italics

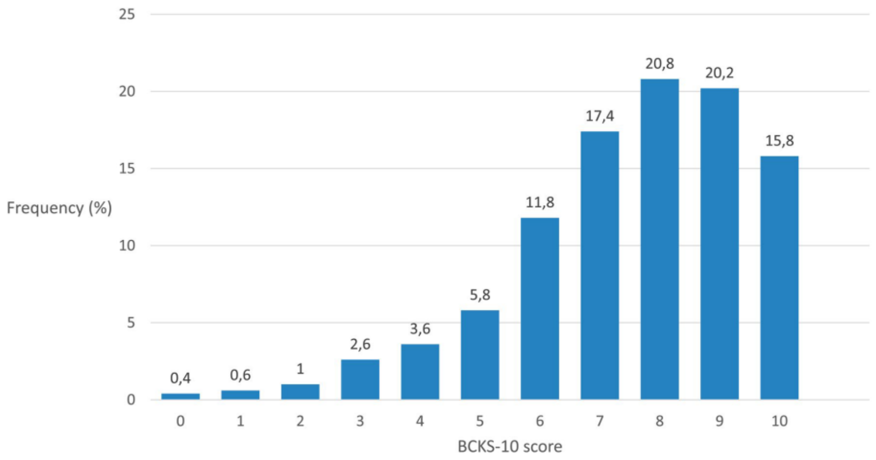

Fig. 1 Distribution (%) of the BCKS-10 score ($N=500$)

Table 2 Distribution characteristics and internal consistency of the BCKS-10

n	M	SD	Mdn	Range	Skewness	Kurtosis	Shapiro–Wilk-test[a]	Cronbach's α
500	7.53	1.98	8	0–10	− 0,954	0.901	0.140	0.680

M mean, *SD* standard deviation, *Mdn* median

[a] Test on normality of distributions

Table 3 BCKS-10 score (range 0–10), cancer site, education and migration background

	M ± SD	p
Cancer site		
Prostate	7.44 ± 2.17	0.288
Breast	7.71 ± 1.94	
Bladder	7.85 ± 1.85	
Colorectum	7.78 ± 1.67	
Leukaemia, lymphoma and myeloma	7.11 ± 1.66	
Education		
Low	6.10 ± 2.55	< 0.001
Middle	7.06 ± 1.97	
High	7.57 ± 1.68	
Very high	8.08 ± 1.98	
Migration background		
Yes	7.15 ± 2.55	0.193
No	7.57 ± 2.48	

Including the five most frequent cancer sites in the sample

M mean, *SD* standard deviation

p values are derived using univariate ANOVA

0.680 (Table 2). Deleting items resulted in no improvements in Cronbach's alpha value.

Discussion

This study aimed to introduce the development and psychometric properties of a brief general cancer knowledge scale for patients independent of cancer site and stage among a sample of cancer patients in Germany. Overall, the findings of the study provide evidence that the psychometric properties of the BCKS-10 are satisfactory. In previous literature, there is no consensus about the interpretation of Cronbach's alpha values [22]. Mostly, a value ≥ 0.7 is rated as an acceptable threshold for reliability [19], but it is highly affected by the test length and dimensionality. The internal consistency in our study is about 0.68. Given the fact that scale only consists of 10 items, and that we introduce a knowledge scale that aims to test for discrete elements of knowledge and understanding in different dimensions and areas, the internal consistency can

Table 4 Item difficulty and item discrimination of the BCKS-10 ($n=500$)

Item	Item difficulty (range 0–1)	Item discrimination (corrected item-total correlation) (range 0–1)
1. A tumour stage I means	0.758	0.322
2. A drug is effective in 80% of those treated. That is, in how many people does it not work?	0.876	0.386
3. You have read that the incidence of adverse effects is 5%. What does that mean?	0.878	0.264
4. True or false? Palliative care aims to cure cancer	0.906	0.414
5. Rebecca was treated for breast cancer (stage II). There is a 10% chance that the cancer will come back in the next 10 years. If Rebecca takes a new drug, this probability is reduced by 30%. In how many out of 100 women taking the drug, like Rebecca, will the breast cancer come back in the next 10 years?	0.432	0.348
6. What is a metastasis?	0.990	0.244
7. What are cytostatics?	0.830	0.413
8. What is meant by a colonoscopy? An examination	0.832	0.336
9. Max utilize a cancer screening. This shows a conspicuous finding. However, the subsequent examination shows that Max does not have cancer. What is the term for such an early detection result?	0.522	0.384
10. What does the term "adjuvant therapy" mean?	0.502	0.396

be seen as satisfactory [22]. In terms of item difficulty the range is from 0.43 to 0.99. Two items were correctly answered by more than 90% of the respondents. Upon the advice of the experts specifically from the patient organisations, we kept these items in the instrument, as solely items with a high difficulty potentially leads to frustration and dropout among the participants. Furthermore, no improvements in Cronbach's alpha was achieved when deleting one of the items. Ceiling effects are considered to be present if more than 15% of respondents achieved the highest possible score [23]. In our study, 15.8% achieved a score of 10. Thus, a low ceiling effect cannot be ruled out. However, as higher educated patients are overrepresented in the sample, interpretations about the difficulty score should be done carefully. Further, an item-total correlation lower than 0.3 is not desirable [19]. In the present study, the values range from 0.24 to 0.41 including two items lower than the threshold. This could be seen as a limitation, however, the majority of the items showed an acceptable value. Construct validity is supported by the results regarding expected differences in knowledge scores among the sample. First of all, there is no difference in terms of cancer site. This is a relevant precondition as the instrument is meant to be generic for patients with cancer. In addition, the inclusion of interview and survey data among experts in the field highly contributed to the scale development and its validity. Furthermore, a clear and significant educational gradient was shown, as well as lower values among patients with migration background, although not significant. Concerning the participants with migration background, we have to add that these are supposed to be highly integrated and thus not representative for migrants in Germany as a whole, as they had a higher education, were following the request to participate in this study, and as they were in command of German language.

The BCKS-10 contributes to the current evidence of the assessment of cancer knowledge as there are only very few instruments that are brief, generic and addressed to cancer patients including different elements of knowledge and skills in terms of terminology, diagnosis, treatment, prevention and numeracy. While the validated CHLT-30 and the CLS were too long regarding the aim of a brief assessment, the also validated CHLT-6 lacks questions regarding treatment options and their terminology which was reported as relevant by the experts in our interviews and the survey [11, 17]. Further cancer knowledge tests lack data on reliability and validity, are based on specific cancer sites or solely assess reading abilities and numeracy [8, 24]. In the German version, three nation-specific items concerning legal matters of administration and health care system can be additionally included in the test, as facilitating of navigation within the health care system is one of the major recommendation of The German National Action Plan Health Literacy [25]. It is a suitable and convenient test that can be easily introduced in surveys among patients with cancer. The instrument is designed to quickly identify patients with limited and increased cancer literacy, and it allows to identify differences between subjective and objective measurements of knowledge and understanding of cancer in a survey.

Several limitations of the study have to be considered. Despite the multi-channel approach of participants' recruitment, the sample cannot be regarded as representative for the whole collective of cancer patients in Germany. A selection bias cannot be ruled out as the sample predominantly consist of participants with a higher educational level and no migration background which may reduce the validity. Yet, low response rates among patients with lower education and migration background are common and still a relevant issue in survey research. The recruitment of patients with a chronic disease like cancer during the COVID-19 pandemic met numerous obstacles and diminished the quality of the sample. Therefore, the BCKS-10 should be applied and tested among further samples of cancer patients to confirm and potentially improve its psychometric properties. Additionally, solely the German version is tested in this study. However, the high percentage of previous or current members of peer support groups did not bias the results. An additional conduction of ANOVA revealed no significant differences in the BCKS-10 score between members and non-members ($p = 0.237$). Moreover, a further testing of construct validity by comparing the results with other established knowledge scales in a survey is recommended. Some values regarding the item difficulty and discrimination deviate from the common threshold which is already discussed above, and which also requires further surveys that include the BCKS-10 to improve the evidence. Nevertheless, our results suggest that the BCKS-10 is a suitable tool to briefly assess the knowledge of cancer among patients including different elements of knowledge. Instruments for cancer patients that are designed like the BCKS-10 are very rare and contribute to the investigation of cancer literacy, its education and improvement.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10552-022-01601-x.

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Author contributions All authors contributed to the study conception and design. JK drafted the manuscript, and analysed the data. EZ, CK and JK subsequently interpreted the data. EZ, CK and JK also developed the survey among the peer group leaders. EZ conducted the expert interviews and developed the instrument. CK and JK were included in further development process, CK led the project. All authors critically revised and approved the final manuscript.

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Data availability The datasets generated during and/or analysed during the current study are not publicly available due to protection of data privacy.

Declarations

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Local Psychological Ethics Committee at the Center for Psychosocial Medicine, University Medical Center Hamburg (No. LPEK-0109).

Consent to participate Informed consent was obtained from all individual participants on the basis of study information and data privacy statement.

Consent to publish Informed consent regarding publishing was obtained from all individual participants included in the study.

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Supplementary information

The BCKS-10 questionnaire (correct answers in bold)

1. A tumour in stage I means…

- **small or medium-sized tumours**
- tumours with metastases
- tumours with lymph node involvement
- tumours with distant metastases
- don't know

2. A drug is effective in 80% of those treated. That is, in how many people does it *not* work?

- 80 out of 100
- **20 out of 100**
- 8 out of 100
- 2 out of 100
- don't know

3. You have read that the incidence of adverse events is 5%. What does that mean?

- The majority of people will experience the adverse event.
- **There is a chance that an adverse event will occur in 5 out of 100 people.**
- An adverse event will occur during 5 out of 100 days.
- The severity of the adverse event is 5%.
- don't know

4. True or false? Palliative care aims to cure cancer.

- true
- **false**
- don't know

5. Rebecca was treated for breast cancer (stage II). There is a 10% chance that the cancer will come back in the next 10 years. If Rebecca takes a new drug, this probability is reduced by 30%. In how many out of 100 women taking the drug, like Rebecca, will the breast cancer come back in the next 10 years?

- 3 out of 100 women
- **7 out of 100 women**
- 10 out of 100 women
- 30 out of 100 women
- don't know

6. What is a metastasis?

- surgical procedure
- scientific analysis
- **secondary malignant growth**
- drug
- don't know

7. What are cytostatics?

- surgical procedures
- benign tumours
- secondary malignant growth
- **tumour-active drugs**
- don't know

8. What is meant by a colonoscopy? An examination...

- of the stomach
- of the brain
- of the blood
- **of the intestine**
- don't know

9. Max goes for a cancer screening. This shows a conspicuous finding. However, the subsequent examination shows that Max does not have cancer. What is the term for such an early detection result?

- correct positive
- **false positive**
- correct negative
- false negative
- don't know

10. What does the term "adjuvant therapy" mean?

- a treatment before the actual intervention (e.g. surgery)
- a treatment that directly targets the cancer
- a pure chemotherapy without surgery
- **a further treatment after the primary therapy (e.g. after the removal of a tumour)**
- don't know

7. Publication 3

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RESEARCH

Do members of cancer peer support groups know more about cancer than non-members? Results from a cross-sectional study in Germany

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Abstract

Purpose This study aims to assess whether cancer-specific knowledge (CSK) is associated with membership in a cancer peer support group (PSG) and other factors.

Methods A cross-sectional study investigated the CSK of 1121 cancer patients of various entities across Germany. CSK was measured with the BCKS-14, a 14-item knowledge instrument which was previously participatory developed with patient representatives and oncologists. Associations between CSK and PSG membership, sociodemographic factors, internet use, and preferences in medical decision-making were analysed with *t*-tests and multiple linear regressions.

Results The *t*-test showed a statistically significant difference in CSK between members and non-members of PSGs. Knowledge for PSG members was on average 0.97 points higher ($p < 0.001$) and varied between 2 and 14 points compared to 0–14 points for non-members. Regression analysis revealed age, gender, time since diagnosis, education, internet use, and PSG activity to be statistically significant predictors. Younger ($\beta = -0.15$; $p < 0.001$), female ($\beta = 0.10$; $p = 0.001$), higher educated patients ($\beta = 0.27$; $p < 0.001$) with and a diagnosis longer ago ($\beta = 0.10$; $p = 0.002$) who use the internet frequently for information seeking ($\beta = 0.20$; $p \leq 0.001$) and members of cancer PSGs ($\beta = 0.18$; $p \leq 0.001$) showed a higher CSK.

Conclusion Overall, CSK of the participants shows a high degree of variance. CSK should be promoted for all patients and especially for older, newly diagnosed patients with low educational levels and PSGs introduced early on as they contribute to improving CSK among other benefits.

Keywords Oncology · Cancer · Knowledge · Health literacy · Peer support · Self-help groups

Introduction

Disease-specific knowledge is a core component of cancer patients' health literacy and thus highly relevant for making informed decisions [1]. It is associated with effective self-management [2] and can consequently improve physical and mental outcomes [3–6]. As a result, it can foster empowerment of patients [7]. However, studies indicate that many cancer patients lack cancer-specific knowledge [4, 8–10], or that patients feel like they do not know enough about the complex treatment options, side effects, and the care system [11]. This in turn has implications for patients' decision-making and the course of the disease [10].

Cancer peer support groups (PSGs) have the potential to improve patients' disease-specific knowledge through shared informational support [12, 13]. Cancer peer support provided in groups of individuals with the same disease who meet outside professional settings and without hierarchical relationships has therefore become a crucial part of effective supportive oncological care. With regard to who is joining a PSG, several studies have shown that patient characteristics such as age, gender, socioeconomic status, education, disease duration, and social support have an influence on the decision whether to participate in a PSG or not [14–18]. However, studies assessing the predictive value of these factors relating to participation in PSGs produced ambiguous results [14–18]. Concerning cancer-related knowledge, studies similarly identified especially female and elderly patients, and those with lower education to be at risk for having insufficient knowledge to effectively manage their disease [4, 6, 19].

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To date, it has not yet been sufficiently studied how much patients inside and outside of PSGs know about cancer. Next to some qualitative studies on this topic [20, 21], there are only few quantitative studies comparing cancer-related knowledge between PSG members and non-members and have various limitations. Most of these studies examine only one gender-specific entity like breast or prostate cancer [8, 22–27], so that differences due to gender are not assessed and have only small sample sizes [22, 28]. Further, the instruments used in these studies are often subjective self-assessments [22, 23, 28–30] rather than objective knowledge tests and not validated [25, 30]. Lastly, the existing instruments were not developed with patients for patients and may therefore not be appropriate for all cancer patients.

Against this backdrop, we use a newly, participatory developed brief cancer knowledge scale (BCKS-14). It comprises cancer-specific knowledge content considered as relevant for patients of all cancer entities from the view of patients. We aim to assess firstly, how cancer-related knowledge is associated with participation in PSGs to investigate whether members of PSGs know more about cancer than non-members. Secondly, we explore which other factors are associated with higher or lower cancer-specific knowledge.

Methods

Study design and population

A cross-sectional study with a self-administered questionnaire was conducted between October 2020 and September 2021 to examine cancer-related knowledge among cancer patients across Germany. The research is part of a larger study investigating health literacy, self-help activities, and care experiences of cancer patients. The study was based on a participatory research approach and conducted in cooperation with the House of Cancer Self-Help–Federal Association (HCSH), an association of ten nationwide operating cancer peer support organisations (PSOs) funded by the German Cancer Aid Foundation. Ethical approval was obtained from the Local Psychological Ethics Committee at the Centre for Psychosocial Medicine, University Medical Centre Hamburg (No. LPEK-0109).

Recruitment of patients commenced in October 2020, following a multi-channel approach sending more than 60,000 pamphlets and posters containing study information to over 1382 cancer care facilities for acute, supportive, and after care across Germany. The study material provided a link and QR code to participate in the survey online as well as a telephone number and e-mail address for patients who might wish to use a paper–pencil version of the questionnaire, which was then sent to them by post and could be returned anonymously. The care and counselling facilities such as regional cancer societies, cancer counselling centres, oncological rehabilitation clinics, certified cancer centres, hospitals with oncological departments, and oncological specialised practices as well as peer support organisations were informed in advance about the study by post.

Snowball sampling of patients also took place though the HCSH, peer support groups outside of PSOs, and the German Cancer Society, asking them to circulate the call for study participation (by e-mail, post and PSO-journals). Further, information about the study was shared through a newsletter of the National Contact and Information Centre for the Initiation and Support of Self-Help Groups and at a virtual patient congress. Reminder e-mails were sent out in February and May 2021 to optimise response rates. Eligible participants were German-speaking members and non-members of PSGs that are patients 18 years and older, with any cancer diagnosis at any stage, regardless of gender and treatment received. All participants provided informed consent by confirming to have read the study information and data protection regulations.

Instruments and variables

Data for this study are collected using a self-administered questionnaire which is part of a larger questionnaire focussing on nine topics: diagnosis and treatment, care experience, self-help activity, health literacy, coping and self-management, social support and quality of life, economic situation, religiosity/spirituality, Covid-19, and sociodemographic information. The survey questionnaire was created in collaboration with medical representatives of oncology, representatives of medical sociology, the German Cancer Society, members of HCHS and PSOs, peer support researchers, and self-help clearing houses.

Outcome variable

Cancer-related knowledge as the independent variable was measured using a 14-item questionnaire (BCKS-14) (see Appendix) previously developed by the authors. It represents the extended version of the BCKS-10 which was validated in a sample of 500 cancer patients and showed satisfactory internal consistency (Cronbach's $\alpha = 0.68$) [31]. The BCKS-14 contains four additional nation-specific items about German (social) legislation and patient rights and showed similar psychometric properties (Cronbach's $\alpha = 0.68$). The brief cancer knowledge scale includes cancer-specific elements of knowledge about terminology, diagnosis, treatment, (social) legislation, and numeracy that were identified as crucial for patients in a previous study by PSG leaders. For analyses, we coded the correct answers as '1' and both the incorrect and the 'don't know' answers as '0' and built a sum score ranging from 0 to 14 points. Thus, patients received 1 point per correct answer and could reach a maximum of 14 points if all answers were answered correctly (see Appendix). We accepted up to three missing answers, which were imputed for building the sum score, so if more than three answers were missing, the respondent was counted as missing.

Independent variables

To measure patients' preference regarding medical decision-making, we used a modified version of item 13 of the Patient Participation Questionnaire [32] in order to assess their general attitude towards different models of decision-making. Patients were asked to indicate who should make the medical decisions for their disease, ranging between 1 (active, informed decision-making model preference; 'I should decide'.) and 5 (equivalent to passive, paternalistic model preference; 'The doctor should decide',). To assess internet use for cancer information, patients were asked to position themselves on a 4-point scale to indicate how intensively they have used information from the internet to inform themselves about cancer, ranging from 1 'almost exclusively' to 4 'not at all'. For the analyses, values for decision-making preference and internet use were reversed so that the scales range from passive/less frequent to active/more often.

Other predictors comprised patient sociodemographic characteristics (gender, age, education, and relationship status as a proxy for social support), clinical history (time since diagnosis) as well as PSG activity (membership). PSG membership was dichotomised into 'currently a member of a PSG' and 'never been a member of a PSG'. Partnership status was also dichotomised into having a spouse or partner/not having a spouse or partner. Age and time since diagnosis were coded in years as continuous variables. School education was coded into high, medium, and low, representing ≤ 9 years of education (no qualification or lower secondary school leaving certificate, *Hauptschulabschluss*), 10 years of education (*Realschulabschluss*), and ≥ 11 years (*Fachhochschulreife/Abitur*) level of education.

Statistical analyses

Data analysis was performed using IBM SPSS Statistics 26. Descriptive statistics were used to examine clinical and sociodemographic characteristics of patients and the distribution of scores of the outcome variables. Two-tailed independent *t*-test was used to evaluate the difference in knowledge scores between PSG members and non-members adjusting for multiple testing according to Holm's procedure [33]. Multiple linear regression was used to determine potential associations between knowledge scores, PSG membership, time since diagnosis, internet use, decision-making preference, and sociodemographic variables such as gender, age, education, and partnership. The statistical significance was set to an alpha level of 0.05.

Results

Sample characteristics

A total of 1356 patients participated in the study. We excluded respondents with missing data for items regarding the sociodemographic characteristics. After data cleaning, 1121 patients who completed the questionnaire remained in the data set. Table 1 summarises the characteristics of these respondents. Patients from all federal states of Germany participated, most of them from North Rhine-Westphalia, the federal state with the biggest population in Germany. Newly diagnosed patients as well as cancer survivors participated, on average 4.6 ± 6.0 years after the cancer diagnosis. The mean age was 61.3 ± 12.4 years. The percentage of female participants was 54.7%. Most respondents had a high level of education (58.3%), which is almost twice as high as German general population in 2018 [34] and were living in a partnership (83.2%), compared to 60% in the general population [35]. Nearly a third of the respondents were breast cancer patients (30.6%) followed by prostate cancer patients as the second most common cancer type (19.3%). The cancer stages varied from UICC (Union Internationale Contre le Cancer) stage 0 to stage IV, with most patients not knowing their stage of the disease (43.5%).

Nearly half of the participants were members of PSGs (45.2%). Their membership reached from less than a year up to 42 years, with an average membership of 15.0 years. Comparing PSG members with non-members, both groups had a similar education status and the decision-making preference. All patients prefer shared-decision-making for medical decisions followed by the informed decision-making model. However, there are significant differences in age, gender, cancer type, and time since diagnosis among the groups, with PSG members being mostly males and older, with a diagnosis on average 6 years longer ago compared to non-members. More PSG members are prostate cancer survivors who completed treatment. More frequent internet use for cancer-related information seeking is slightly higher among PSG members. Further, there are statistically significant differences with minimal effect sizes regarding partnership status and UICC stages but with overall similar distributions across both groups.

Table 1 Characteristics of the patients ($N = 1121$)

Variable	Patients, *n* (%) or mean (SD)	PSG-members, *n* (%) or mean (SD)	Non-members, *n* (%) or mean (SD)	*p*
Age (years)	61.3 (±12.4)	65.7 (±11.5)	57.5 (±11.9)	**.000**[a]
21–39	66 (5.9%)	19 (3.8%)	46 (7.7%)	
40–59	400 (35.7%)	109 (22.1%)	285 (47.5%)	
60–79	589 (52.5%)	320 (64.8%)	251 (41.8%)	
≥ 80	66 (5.9%)	46 (9.3%)	18 (3.0%)	
Gender				**.000**[b]
Male	507 (45.3%)	304 (61.5%)	188 (31.4%)	
Female	613 (54.7%)	190 (38.5%)	411 (68.6%)	
Education				.442[b]
Low (≤ 9 years)	135 (12.2%)	59 (12.0%)	74 (12.6%)	
Medium (10 years)	326 (29.5%)	138 (28.1%)	184 (31.3%)	
High (≥ 11 years)	645 (58.3%)	294 (59.9%)	330 (56.1%)	
Partnership				**.048**[b]
No	184 (16.8)	69 (14.2%)	109 (18.8%)	
Yes	909 (83.2%)	416 (84.2%)	472 (81.2%)	
Primary cancer type				**.000**[b]
Breast cancer	337 (30.6%)	89 (18.1%)	243 (41.7%)	
Prostate cancer	212 (19.3%)	151 (30.6%)	55 (9.4%)	
Bladder cancer	91 (8.3%)	72 (14.6%)	15 (2.6%)	
Colorectal cancer	77 (7.0%)	37 (7.5%)	39 (6.7%)	
Leukaemia	39 (3.5%)	20 (4.1%)	19 (3.3%)	
Lymphoma	37 (3.4%)	13 (2.6%)	22 (3.8%)	
Lung cancer	32 (2.9%)	10 (2.0%)	22 (3.8%)	
Bone marrow cancer	28 (2.5%)	13 (2.6%)	14 (2.4%)	
Thyroid cancer	28 (2.5%)	14 (2.8%)	13 (2.2%)	
Skin cancer	24 (2.2%)	10 (2.0%)	14 (2.4%)	
Laryngeal cancer	23 (2.1%)	18 (3.7%)	4 (0.7%)	
Kidney cancer	22 (2.0%)	4 (0.8%)	18 (3.1%)	
Other (overall each less than 2%)	150 (14.2%)	42 (8.5%)	119 (20.4%)	
UICC stage				**.032**[a]
0	16 (1.5%)	8 (1.7%)	7 (1.3%)	
I	114 (11.0%)	47 (10.1%)	64 (11.7%)	
II	160 (15.4%)	75 (16.1%)	83 (15.2%)	
III	210 (20.3%)	101 (21.7%)	101 (18.5%)	
IV	86 (8.3%)	52 (11.2%)	34 (6.2%)	
do not know	451 (43.5%)	182 (39.1%)	257 (47.1%)	
Time since diagnosis	4.6 (±6.0)	7.7 (±6.5)	1.8 (±3.5)	**.000**[a]
≤ 1 year	345 (30.9%)	35 (7.1%)	310 (51.8%)	
1–4 years	370 (33.1%)	153 (31.0%)	210 (35.1%)	
≥ 5 years	403 (36.0%)	305 (61.9%)	78 (13.0%)	
Peer support group membership				
No	600 (54.8%)	0 (0%)	600 (100%)	
Yes	494 (45.2%)	494 (100%)	0 (0%)	
Knowledge score	9.4 (±2.6)	10.0 (±2.3)	9.0 (±2.8)	**.000**[a]
Medical decision-making preference				.133[b]
Paternalistic model	69 (6.2%)	23 (4.7%)	45 (7.6%)	
Shared decision-making	841 (76.0%)	373 (76.6%)	448 (75.5%)	
Informed decision-making	197 (17.8%)	91 (18.7%)	100 (16.9%)	
Internet use for information				**.009**[b]
Not at all	164 (14.7%)	53 (10.8%)	107 (18.0%)	
Rarely	399 (35.8%)	187 (37.9%)	206 (34.6%)	
Mainly	466 (41.8%)	216 (43.8%)	236 (39.7%)	
Almost exclusively	86 (7.7%)	37 (7.5%)	46 (7.7%)	

Significant differences are highlighted in bold

[a] *t*-test

[b] chi^2-test

Unpaired t-test for independent samples (Welch's t-test due to inhomogeneity of variance)

A *t*-test was performed to detect meaningful differences between PSG members and non-members in cancer-specific knowledge. Both groups were not normally distributed, as assessed by the Shapiro–Wilk test ($p < 0.001$) and Kolmogorov–Smirnov test. However, due to large sample sizes ($n > 30$) for each of the two groups, normally distributed means were assumed and parametric tests appropriate be used [36, 37]. There were 494 (members) and 600 (non-members) participants with valid data for the knowledge test in the groups ($n = 1{,}094$). Cancer-specific knowledge scores ranged from 0 to 14 points in non-members and from 2 to 14 points among PSG members. Knowledge sum scores of the 14 items in total were higher among members ($M = 9.94$, $SD = 2.34$) than non-members ($M = 8.96$, $SD = 2.79$) (Fig. 1). The Levene test became significant, and thus, there was no variance homogeneity for the two groups (variances are not equal), so the Welch test statistic was assessed. There was a statistically significant difference between overall knowledge scores of PSG members and non-members, with mean knowledge scores 0.97 points (95%-CI = 0.67–1.28) higher for PSG members, t(1081.84) = 6.25, $p < 0.001$.

Comparison of mean knowledge scores between PSG members and non-members regarding the individual knowledge questions (single items) revealed significant higher scores of PSG members than non-members in 7 out of 14 items (questions 4, 7, 8, 9, 10, 11, and 13). Those differences were however marginal. Besides, PSG members scored marginally worse than non-members on items 6 and 12; however, those differences are not statistically significant. The largest significant differences were visible in questions 8, 9, and 11; each showed a mean score difference of > 0.10) in favour of the PSG members (Table 2).

Multiple linear regression

To determine more comprehensively the association of PSG membership and other factors on cancer-specific knowledge, a multiple linear regression was performed. The regression model includes cancer-related knowledge as the outcome variable and nine explanatory variables as presented in Table 3. Prior to the analysis, we checked for normality, linearity, multicollinearity, and independence of residuals — no concerns were found. Indicating a normal distribution, the analysis revealed the model to be a good fit to the data ($F(8{,}1024) = 40.94$, $p < 0.001$), being statistically significant and explaining 24% of the variability in the dependent variable (adjusted $R2 = 0.24$). Of the predictor variables, age, gender, time since diagnosis, education, PSG activity, and internet use were found to be statistically significant. Younger ($\beta = -0.15$, $p \leq 0.001$), female patients ($\beta = 0.10$, $p = 0.001$) and those with a diagnosis longer ago ($\beta = 0.10$, $p = 0.002$) were more likely to have higher cancer-related knowledge. Further, the higher the educational level ($\beta = 0.27$, $p \leq 0.001$), the higher is the knowledge score. Lastly, members of PSGs and patients who use the internet more for accessing cancer-related information hold higher overall disease-specific knowledge scores ($\beta = 0.18$, $p \leq 0.001$ and $\beta = 0.20$, $p \leq 0.001$).

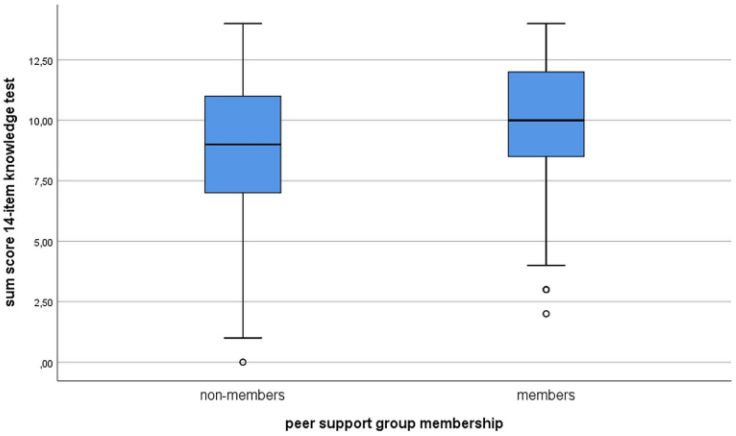

Fig. 1 Sum score comparison of knowledge test for members and non-members of peer support groups ($n = 1094$)

Table 2 Mean score differences (t-tests) among peer support group members and non-members ($n=1094$)

Item	Mean score difference	95%-CI	p
Definition of tumour stage I	0.06	0.00–0.11	0.190
Allocation of 80% drug efficacy	0.04	−0.00–0.09	0.320
Meaning of 5% incidence	0.02	-0.03–0.06	1.000
Aim of palliative care	0.07	0.03–0.11	**0.007**
Calculation of risk reduction	0.05	−0.01–0.11	0.427
Definition of metastasis	−0.00	−0.01–0.01	1.000
Definition of cytostatics	0.10	0.05–0.15	**< 0.001**
Definition of colonoscopy	0.18	0.13–0.23	**< 0.001**
Allocation of false positive result	0.12	0.06–0.18	**0.001**
Definition of adjuvant therapy	0.09	0.03–0.15	**0.020**
Recommended start of follow-up treatment	0.22	0.17–0.28	**< 0.001**
Maximum duration sick pay	−0.05	−0.11–0.01	0.427
Application for a disabled person's card	0.07	0.02–0.11	**0.021**
Patients' rights	0.02	−0.04–0.08	1.000

Adjusted for multiple testing (Holm's procedure), significant differences are highlighted in bold

Table 3 Linear regression model examining cancer-related knowledge ($n=1032$)

Independent variables	Regression coefficient B	Standard error	Standardised regression coefficient β	95%-CI	p
Age	−0.031	0.007	−0.152	−0.05 to −0.02	**< 0.001**
Gender	0.535	0.166	0.103	0.21–0.86	**0.001**
Years since diagnosis	0.045	0.014	0.101	0.02–0.07	**0.002**
Education	1.010	0.106	0.273	0.80–1.22	**< 0.001**
Partnership	0.056	0.194	0.008	−0.33–0.44	0.773
Peer support group membership	0.915	0.168	0.176	0.59–1.24	**< 0.001**
Decision-making preference	0.048	0.111	0.012	−0.17–0.27	0.666
Internet use	0.640	0.091	0.203	0.46–0.82	**< 0.001**

Significant variables are highlighted in bold

Discussion

The patient groups representing PSG members and non-members in this study were heterogeneous but similar in terms of education levels, decision-making preference, relationship status, and internet use for information. In both groups, cancer knowledge showed a wide range and overall moderate to high average knowledge scores ($M=9.94$ among members and 8.96 of non-members). This means, on average, the patients have answered at least 9 out of 14 questions correctly. The overall knowledge levels detected in this study seem to contradict the finding from Fagerlin et al. [8], who found that the majority of recently diagnosed breast cancer patients had generally low knowledge to make informed decisions about breast cancer and treatment options. Yet, this indicates that before and shortly after diagnosis, cancer-relevant knowledge is most likely still low and increases in the further course of the disease and its treatment. This is consistent with our finding that the time since diagnosis correlates highly significantly with the knowledge index.

The present results also show that cancer-specific knowledge was significantly higher among PSG members compared to non-members. Thus, they support the findings of prior research that concluded that PSGs indeed contribute to extended cancer information among their members [24, 25, 27]. However, although the mean difference between the groups in our study was significant, it was rather small. PSG members on average have answered only one more knowledge question correctly than non-members. This raises the question of how far this difference presents a practical relevance. Considering the fifth of a standard deviation as often suggested by the literature to estimate the minimally important difference (MID) with a small effect size [38–40], the 0.97 point difference in our data exceeds the determined MID of 0.53. Thus, we can assume a small effect but meaningful difference for cancer care. This finding is in line with the above cited studies [24, 25, 27], which also found small to moderate but significant effects when comparing cancer PSG members' with non-members' knowledge, even after controlling for sociodemographic variables.

Further studies, which did not find any difference between PSG-members and non-members regarding objective cancer knowledge, however found subjectively perceived improvements in knowledge through the PSGs [16, 26]. Similarly, Sheppard et al. [28] reported that PSG participants subjectively felt better informed than non-participants, concluding that PSGs can also foster patients' empowerment. Overall, these results demonstrate the importance of PSGs, providing not only emotional support but informational support as well. Nevertheless, considering that the questions asked in this study were overall not too challenging as assessed by the item difficulty index of the BCKS [31], the large range of knowledge scores and average sum scores should have been higher among both groups.

Other factors associated with higher levels of cancer knowledge despite PSG activity as revealed in the regression analysis were age, time since diagnosis, gender, education, and internet use. In comparison to the other factors, the association of PSG membership with cancer knowledge was weaker than the association with other factors, as reported previously [25] as well. This might stem from the fact that PSGs are not necessarily systematic training programmes targeting knowledge as the primary aim, but rather provide informational support as one of several other aspects such as emotional support. Yet, it represents the third strongest predictor on knowledge in our regression model (peer support members achieve one point more in the knowledge score, as indicated by the beta values).

The association between educational level and cancer knowledge is the highest compared to the other predictors in our data, as higher educated patients achieve one point more on the knowledge scale, as shown by the beta values. It is not surprising that patients with higher education hold higher disease-specific knowledge and this finding was equally reported previously [6, 25], who also highlight education being a stronger predictor on total knowledge scores than PSG membership. Noeres et al. [27] on the other hand identified PSG involvement as most decisive for participants' knowledge but also acknowledge the effects of age and education. Thus, it can be concluded that the impact of a PSG on cancer knowledge is an additional stand-alone factor similar to age, disease duration, gender, or internet use. The analysis further revealed that internet use is positively associated with cancer-related knowledge, which reflects the assumption that over the last two decades, the internet has become a meaningful source for cancer information and thus cancer knowledge. Here, the standardised beta values indicated internet use to be the second strongest predictor (achieving more than 0.5 points more on the knowledge scale, if used more frequently). This result supports the findings of other authors [4, 8], who found that internet use or daily internet access improves cancer knowledge.

Interestingly, a steady relationship as an indicator of social support did not predict cancer knowledge, while other studies did find social support to have an impact [41]. Our finding may suggest that the patients' partners are not well informed either or that they have not been sufficiently involved in the patients' cancer history. Nonetheless, further studies have shown that including partners or relatives in treatment and care indeed improves communication and patients' compliance as they often have more capacities to absorb and remember relevant disease-specific information than the patients themselves, specifically in their overwhelming situation [42, 43]. As shown in our analyses, older patients tend to hold less disease-specific knowledge, possibly due to lack of recall of information and effective communication with health care providers [44] and because they might be less likely to effectively obtain information from the internet. Especially for them, it can be helpful, and thus is to be recommended, to include relatives in information provision and also to suggest participation in a PSG to help strengthen cancer-specific knowledge.

Contrary to previous research [6] reporting higher health literacy scores among male patients, female gender predicted a higher cancer knowledge in our study. Here, the association with knowledge was weaker than other predictors, and being female led to achieving merely half a point more on the knowledge test. Moreover, the medical decision-making preference was not significantly associated with cancer knowledge. Thus, the results could not confirm that those patients who prefer an active involvement in medical decision-making with their physicians have higher knowledge scores, although the patients in this sample had overall satisfactory knowledge and preferred a rather active role.

While earlier work from Kühner et al. [25] did not find duration of the disease to have an effect on knowledge levels, we found newly diagnosed patients to hold lower cancer-specific knowledge than those with a diagnosis longer ago. This indicates that in a phase of orientation and acute treatment immediately after the diagnosis, patients are often not able to process all information presented by physicians and others [43] and it may first be a matter of sheer survival. More questions about the disease and its long-term effects such as probability of recurrence, (socio-) legal matters, or dealing with disability only come into focus in the longer run after the first treatment phase or as the patients return to their everyday lives. Our findings therefore indicate that cancer survivors become experts of their illness over time by gathering more information about the disease step by step. Lastly, it is usually not directly after diagnosis but at a later point in time that patients join a PSG, as shown by the patients' characteristics in this study and as revealed by Stevinson et al. [14] which underlines the effect of time since diagnosis on the development of knowledge. Yet, as PSGs have shown to have the potential to improve cancer knowledge, which in turn may impact treatment decision-making, early access to PSGs could be valuable in order to ensure early access to critical cancer-related information.

Limitations

Though the findings provide some evidence for how cancer-related knowledge is associated with participation in PSGs and what other factors are associated with cancer knowledge, there are several limitations of the study that need to be acknowledged. Firstly, although a multi-channel recruitment approach was chosen to include a variety of cancer patients of different ages and stages, the sample is not representative as participants with high educational levels are overrepresented among both groups. Thus, due to the already high level of education of both groups, the PSG membership may have no longer been so decisive for the knowledge levels of the patients, so the identified positive association between knowledge and peer support membership could have even been more prominent among a representative sample. Further, few young patients participated and only literate, German-speaking patients participated, while patients with a migration background are underrepresented. Therefore, there might be a bias in favour of positive reporting, and the knowledge scores across a representative sample with more balanced groups would probably be worse than in our sample.

Secondly, it is to note that the PSG members in our sample were more likely to be men, of older age, and mainly prostate cancer patients, while among non-members, female breast cancer patients were predominant. Thus, a lack of normally distributed groups due to notably differences in age, gender, and cancer type may have led to slightly biased results. Yet, it can be assumed that the results still depict the reality of these groups and that there is no need for a concern of the results' validity of the results due to the large sample sizes. Moreover, we did not assess frequency of participation in PSGs, although this may have also been influential on patients' knowledge. Lastly, we cannot proof causality between PSG participation and cancer-specific knowledge, although it appears plausible that PSG participation increases knowledge.

Lastly, the BCKS-14 does not cover all aspects of knowledge that are shared in PSGs and entails aspects of numeracy knowledge, which is not usually taught in PSGs. It rather focuses on core contents that were identified as central to know by patients. It could be assumed that if a higher number of questions on specific cancer-related knowledge were included on a more extended knowledge scale, the differences between peer support members and non-members would have even been more apparent.

Conclusion

The results indicate that indeed, PSG members know significantly more about cancer than non-members. PSG membership is a relevant factor contributing to higher knowledge with a small effect, while education is the most decisive predictor for cancer-specific knowledge. Since we found large ranges regarding the knowledge scores among both groups, the findings show the need to inform all patients properly. This could be achieved by giving information material on hand and including relatives during the treatment phase, in order to ensure informed patients. Considering that sociodemographic and clinical variables such as time since diagnosis are also associated with cancer-specific knowledge, cancer care providers should further ensure all patients have access to PSGs early on, especially for patients with lower socioeconomic status. For elderly patients in particular, relatives should be involved and PSGs suggested to improve their knowledge and self-management. Further strategies for improving comprehension and recall could contain prioritising and categorising information, using simple language, and presenting information in different formats, e.g., written, face-to-face, or video information.

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Author contribution EZ, CK, and JK designed the study and collected the data. EZ carried out data analysis and interpreted the data. EZ developed the outline and wrote the article with critical remarks by CK and JK. All authors commented on and approved the final version of the manuscript.

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Data availability The datasets used and/or analysed in this study are available from the corresponding author on request.

Declarations

Ethics approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The questionnaire, methodology, and data protection regulations for this study were approved by the Local Psychological Ethics Committee at the Center for Psychosocial Medicine, University Medical Centre Hamburg (Ethics approval number: LPEK-0109).

Consent to participate Informed consent was obtained from all individual participants on the basis of study information and data privacy statement.

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Conflict of interest The authors declare no competing interests.

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Supplementary information

Brief cancer knowledge scale (BCKS-14) (correct answers in bold)

1. A tumour in stage I means...

- **small or medium-sized tumours**
- tumours with metastases
- tumours with lymph node involvement
- tumours with distant metastases
- don't know

2. A drug is effective in 80% of those treated. That is, in how many people does it *not* work?

- 80 out of 100
- **20 out of 100**
- 8 out of 100
- 2 out of 100
- don't know

3. You have read that the incidence of adverse events is 5%. What does that mean?

- The majority of people will experience the adverse event.
- **There is a chance that an adverse event will occur in 5 out of 100 people.**
- An adverse event will occur during 5 out of 100 days.
- The severity of the adverse event is 5%.
- don't know

4. True or false? Palliative care aims to cure cancer.

- true
- **false**
- don't know

5. Rebecca was treated for breast cancer (stage II). There is a 10% chance that the cancer will come back in the next 10 years. If Rebecca takes a new drug, this probability is reduced by 30%. In how many out of 100 women taking the drug, like Rebecca, will the breast cancer come back in the next 10 years?

- 3 out of 100 women
- **7 out of 100 women**
- 10 out of 100 women
- 30 out of 100 women
- don't know

6. What is a metastasis?

- surgical procedure
- scientific analysis

- **secondary malignant growth**
- drug
- don't know

7. What are cytostatics?

- surgical procedures
- benign tumours
- secondary malignant growth
- **tumour-active drugs**
- don't know

8. What is meant by a colonoscopy? An examination...

- of the stomach
- of the brain
- of the blood
- **of the intestine**
- don't know

9. Max goes for a cancer screening. This shows a conspicuous finding. However, the subsequent examination shows that Max does not have cancer. What is the term for such an early detection result?

- correct positive
- **false positive**
- correct negative
- false negative
- don't know

10. What does the term "adjuvant therapy" mean?

- a treatment before the actual intervention (e.g. surgery)
- a treatment that directly targets the cancer
- a pure chemotherapy without surgery
- **a further treatment after the primary therapy (e.g. after the removal of a tumour)**
- don't know

11. When should follow-up rehabilitation or follow-up curative treatment (AHB) for cancer *usually* begin?

- **after completion of the initial treatment (primary therapy)**
- after completion of the secondary treatment (secondary therapy)
- at the earliest 8 weeks after hospital discharge
- at the earliest 6 months after discharge from hospital
- don't know

12. What is the maximum period for which people with statutory health insurance are entitled to sick pay?

- 6 weeks
- 24 weeks
- **78 weeks**
- 2 years
- don't know

13. Where can I apply for a (severely) disabled person's card?

- family doctor
- hospital
- health department
- **pension office**
- don't know

14. As a patient, you have the right to...? Please tick all statements that apply.

- **inspection of the findings (e.g. CT scans, doctor's letters)**
- destruction of your data if you request it
- **free choice of doctor**
- **free choice of your therapy**
- **a second opinion by another doctor**

8. Publication 4

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ORIGINAL ARTICLE

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Self-help friendliness in cancer care: A cross-sectional study among self-help group leaders in Germany

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Abstract

Background: Peer support is increasingly recognized as crucial for improving health and psychosocial outcomes in oncological care. The integration of cancer self-help groups (SHGs) into cancer care facilities has gained importance in recent years. Yet, there is a lack of knowledge of the extent and quality of cooperation between cancer care facilities and SHGs and their integration into routine care. The concept of self-help friendliness (SHF) provides a feasible instrument for the measurement of cooperation and integration.

Methods: A cross-sectional study across Germany investigates the experiences of 266 leaders of cancer SHGs concerning their cooperation with cancer care facilities based on the criteria for SHF. The participatory study was developed and conducted with representatives of the House of Cancer Self-Help and the federal associations of cancer self-help.

Results: According to the SHG leaders, about 80% of their members primarily find their way to an SHG via other patients and only less than 50% more or less frequently via hospitals or rehabilitation clinics. The quality of cooperation with cancer centres, hospitals and rehabilitation clinics, however, is rated as good to very good by more than 70% of the respondents. Nine out of 10 quality criteria for SHF are fully or at least partially implemented, the values vary between 53% and 87%. Overall, 58% of the SHG leaders feel well to be very well integrated into care facilities.

Conclusions: The results show a positive assessment of the involvement of SHGs in oncological care, but differences between inpatient and outpatient care and low referrals to SHGs are prominent. The concept of SHF is a feasible solution for a systematic and measurable involvement of SHGs.

Patient or Public Contribution: The perspectives and insight of patient representatives obtained through qualitative interviews were directly incorporated into this study. Representatives of cancer self-help organizations were involved in the development of the questionnaire, reviewed it for content and comprehensibility, and further helped to recruit participants.

KEYWORDS
cancer care, cooperation, patient involvement, patient participation, peer support, quality management, self-help friendliness

1 | INTRODUCTION

Cancer incidence rates are rising globally, while cancer case fatality has declined over the past years. According to estimates of the GLOBOCAN database provided by the International Agency for Research on Cancer (IARC), there were more than 19 million new cancer cases and nearly 10 million cancer deaths worldwide in 2020.[1] In Germany alone, about 500,000 persons per year are newly diagnosed with cancer.[2] Comparable to worldwide data, the most common cancer in Germany is breast cancer, accounting for 30% of all new cancer cases among women in 2018. The largest proportion of new cases in men is prostate cancer with 24.6% in 2018, followed by colorectal and lung cancer in both sexes with yearly incidences of 9.4–13.3.[2] These entities also represent the largest share of cancer mortality. The median age of disease incidence is 69 years for women and 70 for men, with relative (adjusted for age and general mortality) 5-year survival rates of more than 60% in both groups. The median age at death is 77 years for female and 75 years for male cancer patients in Germany.[2] Children represent a separate patient group with different common diagnoses such as leukaemia, lymphoma and brain tumour, with much lower incidence rates and higher survival rates.[2] Because of demographic change and due to the close association between the risk of cancer and age, the incidence of a cancer diagnosis is increasing.[1] At the same time, in Germany and in all other countries with advanced health care systems, cancer survival rates have significantly improved due to more precise and early diagnostics, and advanced treatment options.[1,3,4]

Next to the highly distressing cancer diagnosis itself, many cancer patients have to face challenges in complex decision-making concerning different treatment options. With regard to the long-term consequences of a cancer diagnosis, psychosocial and economic impacts as well as legal matters, patients require skills and competencies for navigating manifold cancer-related health and social services on offer.[5,6] However, many patients do not have the appropriate knowledge to make informed decisions at the onset of cancer.[7-10] Moreover, directly after the diagnosis, it is difficult for patients to assess the implications of the cancer diagnosis for their everyday lives and their future plans.[10-12] Here, support and advice from other cancer patients is a helpful resource for emotional stabilization and overcoming uncertainty.[13]

Research has shown that cancer peer support for adult patients is an effective complement to professional health care, foremost by providing psychosocial relief and addressing unmet support needs of cancer patients, specifically those related to their daily life.[14-17] It fosters the empowerment of cancer patients to cope better with their disease and to find ways and solutions for adequate self-management.[18,19] The main resource of nonprofessional psychosocial support are cancer self-help groups (SHGs) which are peer support groups of individuals with the same disease who meet outside professional settings in nonhierarchical relationships on a voluntary basis. Most SHGs operate at a regional level and also work as a care policy catalyst to improve the quality of care in the professional health care system. This, in turn, can lead to improved quality of life in cancer patients and better health outcomes.[15,19-21]

In Germany, there are about 100,000 SHGs (predominantly smaller informal groups at a regional level) and nearly 300 more organized health-related self-help organizations (SHOs) at the national level and subdivisions at the federal state level. They cover manifold health-related topics such as cancer.[22] Most of the SHOs are members of nationwide umbrella organizations that represent superordinate collectives. SHGs are supported by a professional self-help support system consisting of more than 300 self-help clearing houses, which maintain additional branch offices providing professional support services for community self-help in 347 locations in Germany. Funding for self-help, of which cancer self-help is a large part, stems mainly from the statutory health and long-term care insurances, the public sector (federal, state and local authorities) and private donors (sponsors and foundations, such as the German Cancer Aid) next to membership fees.[22]

In the framework of patient-centredness, patient participation and patient involvement have become important goals in health care and health care regulations.[23-25] Over the past decades, peer support has been increasingly recognized as a key part of effective supportive care in cancer services. As SHGs represent patient involvement on a collective level,[26,27] the integration of cancer SHGs into oncological care has consequently gained importance in the context of patient-centredness.[28] Thus, and as a response to the ongoing demands of patient groups and organizations, health decision makers made efforts to promote SHGs and to support their integration into routine cancer care,[29-32] where they work as peer counsellors or as patient representatives to enhance the quality of care.

One attempt to strengthen the collaboration between health care providers and SHGs in Germany is represented by the concept of 'Self-Help Friendliness in Health Care'. In 2004, a group of stakeholders within the German self-help system and representatives from various health care institutions started a consensus process over several years with the aim to develop, evaluate and implement quality criteria for sustainable collaboration between health care institutions and patient groups.[33–35] Meanwhile, self-help friendliness (SHF) indicators have been implemented in nearly all quality management systems in health care institutions, first in hospital care, then in outpatient care, later in rehabilitation and finally in public health services.[36] An important, further development in this process was the establishment of the 'Network for Self-Help Friendliness and Patient-Centredness in Health Care' in 2009. The network currently comprises approximately 300 members such as umbrella organizations and hospitals and serves as a model for other countries, resulting in the European Action Alliance for Self-help-Friendliness in 2017, including Austria and Switzerland. Further strategies to foster SHF have been implemented specifically in cancer organizations. The German Cancer Society, for instance, requires the integration of SHGs in oncological care for the certification of cancer centres as one of their quality criteria.[33,37] Similarly, the German Cancer Aid Foundation makes the integration of SHGs in the German Comprehensive Cancer Centres a prerequisite to receiving funding.

Despite increased acceptance of SHGs and peer counsellors by clinicians, and regardless of efforts to improve the collaboration between health care staff and SHGs in cancer care, there is a lack of data regarding the integration of SHGs. Qualitative research has shown that health professionals perceive SHGs as predominantly positive, however, misconceptions about SHGs and lack of collaboration with SHGs still persist.[16,38–40] Studies have further demonstrated that health care professionals play a key role in informing and referring patients to SHGs. They can strongly influence a patient's motivation and decision to join an SHG.[39–43] Thus, overall, a close collaboration between SHGs and health care staff in cancer care is crucial.

This study provides quantitative data on the collaboration between SHGs and cancer care facilities and on the integration of SHGs in cancer care facilities. The evaluation of the extent and quality of collaboration is based on the criteria for SHF from the perspective of patient representatives, namely the leaders of cancer SHGs. Further, it aims to assess if there are commonalities and indicators on the side of the SHGs increasing or decreasing the probability of a good integration in cancer care. Stemming from a patient-oriented research project, the study also investigates how far professionals refer patients to SHGs.

2 | MATERIALS AND METHODS

2.1 | Study design

We conducted a nationwide cross-sectional online survey with leaders of cancer SHGs in Germany. The research is part of a larger study investigating health literacy, self-help activities and care experiences of people with cancer. The study was based on a participatory research approach and was conducted in cooperation with the House of Cancer Self-Help-Federal Association (HCSH), an association of 10 nationwide operating cancer SHOs funded by the German Cancer Aid Foundation. The development of the questionnaire was based on 11 qualitative expert interviews with representatives from the above-mentioned cancer SHOs—most of them long experienced SHG leaders—as well as a literature review. Members of the SHOs participated in the development of the questionnaire and supported the study through the recruitment of cancer-SHG leaders. Recruitment of respondents started in May 2019. The SHG leaders were contacted by e-mail via the SHOs and also by the regional cancer societies to reach SHGs that are not organized in the cancer SHOs. The SHG leaders were provided with all relevant project information in the form of a project flyer, including a link to the project website, and a link to the online-survey questionnaire itself. The HCSH sent reminder e-mails to the SHOs and the regional cancer societies in June and August.

Before data collection, this study was approved by the Local Psychological Ethics Committee at the Centre for Psychosocial Medicine, University Medical Centre Hamburg (No. LPEK-0066). The questionnaire was programmed and deployed online using the Unipark software TIVIAN (formerly Questback). Alternatively, group leaders, who were not willing or able to participate online could request a paper–pencil version or download a PDF document of the questionnaire for their own printout. Before participating in the online survey, the respondents had to read and accept an online form containing the data protection declaration and a consent form. The form contained all necessary information and that all data are treated in accordance with data protection guidelines. Participants were able to participate anonymously. Data were collected between 22 May and 8 September 2019.

2.2 | Study sample

The survey was directed at all SHG leaders of the 10 SHOs and of those registered at the regional cancer societies in Germany. SHGs, defined as self-determined, voluntary groups with the primary purpose of providing support to people with cancer, were considered for this study.

A total of 266 leaders of cancer SHGs participated in the study, ranging from 37 to 84 years of age (Table 1). Paper pencil questionnaires were used by 12 participants, all others used the online version. More than half of the respondents were male. Nearly, three out of four SHGs are part of an SHO. One-quarter of the participants were leaders of prostate cancer SHGs, and a second-quarter consists of SHGs open for several entities, mostly gynaecological cancer types such as ovarian or breast cancer. The SHGs existed for only a few months up to 49 years ($M = 16.3$, $SD = 11.81$).

2.3 | Measures

The questionnaire contained questions on eight domains about the SHGs: general information about the group, goals, and activities of the group, digitization (use of media, internet and challenges), access routes to the SHG, needs of the participants, health literacy of the participants, cooperation with health care providers and patient participation in

TABLE 1 Sociodemographic characteristics of self-help group leaders (*N* = 266)

Variables	Mean	SD	%	*n*
Respondents' age (years)	65.5	9.6		
Existence of SHG (years)	16.3	11.81		
Respondents' gender				
Male			56.4	150
Female			43.6	116
SHG member of an SHO[a]				
Yes			69.9	186
No			10.9	29
Cancer entity[b]				
Various entities			25.6	68
Prostate cancer			24.8	66
Bladder cancer			9.4	25
Colorectal cancer			9.4	25
Laryngeal cancer			7.5	20
Thyroid cancer			4.5	12
Breast cancer			3.4	9
Pancreatic cancer			3.0	8
Leukaemia and lymphoma			3.0	8
Head and neck cancer			2.6	7
Other			1.1	3

Abbreviations: *N*, total number in sample; *n*, number in subsample; SD, standard deviation; SHG, self-help group; SHO, self-help organization.

[a] Missing, *n* = 51.

[b] Missing, *n* = 51.

health care (SHF) and activities as SHG leaders. This article focuses on two of these eight topics, namely access routes to the SHG as well as cooperation and participation as indicators for integration and SHF.

2.3.1 | Access routes to the SHG

The SHG leaders were asked to assess how often patients usually find their way into their group through 11 given channels such as employees of hospitals and rehabilitation clinics; psychotherapists; homepages of the SHO; social media; family/friends/acquaintances and so forth. Frequency categories on a 4-point Likert scale were 'very often', 'often', 'rather seldom' and '(almost) never'.

2.3.2 | Quality of cooperation

SHG leaders had to indicate the perceived quality of collaboration with up to 14 different health care institutions on a 4-point Likert scale ranging from 1 'very good' to 4 'bad'. For those institutions where the SHGs do not have cooperation experience with, peer leaders could choose 'does not apply'. Further, in the sense of patient involvement and to depict the SHG leaders' opinions in more detail, the questionnaire contained two open-ended questions, asking the respondents from their experience, what they perceive as facilitating and hindering factors for cooperation between SHGs and hospitals/cancer care facilities.

2.3.3 | SHF

To assess whether and in how far integration of SHGs takes place at all, the SHF criteria served to operationalize the level of integration. The measurement of SHF in health care institutions was based on the German survey instrument for 'Self-help-oriented Patient-centredness' (SelP-K).[44] The SelP-K has been developed in previous research on the evaluation of SHF in hospitals.[20,45] The items represent the quality criteria that were consensually developed by representatives from self-help and various health care institutions within the framework of the model project 'Quality Seal Self-Help-Friendly Hospital' in Hamburg. The questionnaire was tested and validated within a previous research project.[44,45]

The original SelP-K instrument contains a 10-item subscale measuring the indicators for SHF from the view of health care staff with a very good internal consistency of $\alpha = .93$[44,45] and was adopted for this study. We modified the wording of the 10 statements from the staff's view about SHF in the hospital to the patients' view about SHF in care facilities, keeping the wording as close as possible to the original scale by shifting the focus only where necessary. The 10 items could be answered on a 4-point Likert scale, ranging from 1 'very true' to 4 'not true at all' (see Appendix).[43] The internal consistency of the adapted scale remains very satisfying: $\alpha = .90$.

2.3.4 | Global assessment of integration in health care facilities

One further item used in our study contained a global assessment of the integration of SHGs in health care institutions. SHG leaders were asked how well they feel integrated into care facilities, overall, with a rating on a 4-point Likert scale with either 'poor', 'fair', 'good' or 'very good'.

2.4 | Statistical analyses

Data analysis was performed using IBM SPSS Statistics 26. Due to the explorative nature of the study, descriptive statistics were used to examine the sociodemographic features of the participants, the quality of cooperation and the extent of SHF in cancer care facilities. Bivariate analyses were performed to assess correlations with regard to the relationship between the overall SHF score and other variables of interest. In particular, cross-tabulation analyses (η) were conducted for metric and categorical variables.[46] Spearman's ρ correlations were calculated for ordinal and metric variables.[46,47] For all analyses, the statistical significance was set to an α level of .05.

3 | RESULTS

3.1 | Descriptive analysis

3.1.1 | Access routes to the SHG

We examined how far the professional cancer care system contributes to the referral of cancer patients to SHGs (Figure 1). Nearly 80% of the SHG leaders see other people affected by cancer as the main mediators for finding their way into their SHGs. More than 70% of respondents report that patients often very often access their groups through written material of the SHG such as booklets or flyers. Family, friends, acquaintances and information events are perceived by nearly two-thirds of the respondents as mediators.

However, less than half of the SHG leaders report that people are joining the group often to very often through the recommendation of staff from hospitals or rehabilitation clinics, and the same is true for cancer counselling centres. With regard to (ambulatory) psychotherapists and social media, 85% of the respondents feel that those channels rarely or almost never account for referrals of patients to their groups.

3.1.2 | Quality of cooperation

More than 75% of the SHG leaders cooperate with self-help clearing houses (these are around 340 local counselling centres for SHGs in Germany),[34] hospitals, registered medical specialists, and the German Cancer Aid, Cancer Society and cancer centres. Only 50% or less of the SHGs cooperate with institutions such as health or social welfare authorities, welfare organizations, the Associations of Statutory Health Insurance Physicians (organization and representation of the registered ambulatory physicians), scientists, the Medical Associations (self-administration of all German physicians, responsible for continuing medical education and training, quality assurance, health policy, registration matters) or the Chambers of Psychotherapists.

The quality of cooperation with cancer care facilities such as cancer centres, hospitals and rehabilitation clinics is rated as good to very good by more than 70% of the SHG leaders (Figure 2). In contrast, for registered medical specialists as well as registered psychotherapists in ambulatory practices more than 40% of the SHG leaders rate the cooperation quality as fair or poor.

In free comments to the open-ended questions, 226 SHG leaders named facilitating factors for cooperation with cancer care facilities. These were grouped into 12 themes related to facilitating factors (Table 2). The most often mentioned were personal contact persons or 'key persons' ($n = 57$) with regular exchange 'that you have to work for', as one respondent has written. Further frequent comments were mutual appreciation 'on an equal footing' ($n = 52$), and support for public relations work like distributing pamphlets ($n = 37$). Other facilitating factors, each perceived as important by more than 10 respondents, were formal and documented cooperation agreements, reliable referral of patients to their groups, and available rooms and infrastructure.

Hindering factors were named by 213 SHG leaders and 15 themes emerged (Table 2). The most prominent factors were lack of time of staff ($n = 41$) 'due to high patient numbers', a lack of interest in cancer care facilities ($n = 34$) as well as rejection ($n = 34$), lacking contact and communication ($n = 22$), thoughts of hierarchy and

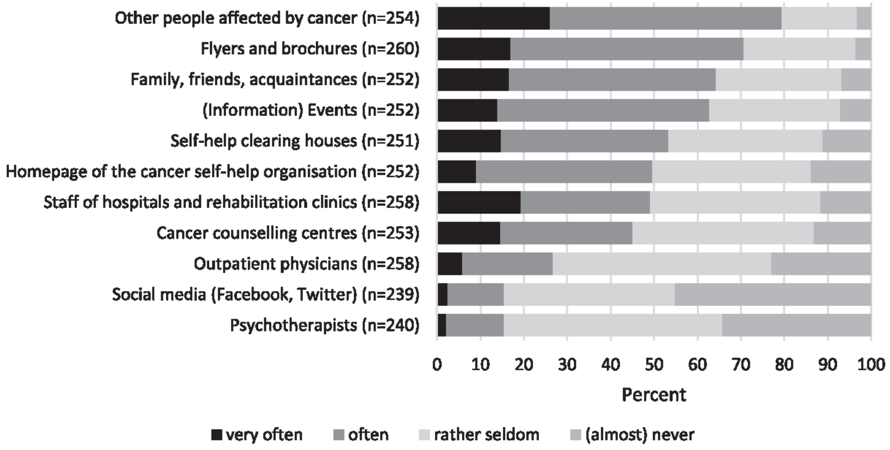

FIGURE 1 Access routes to the self-help groups ($N = 266$)

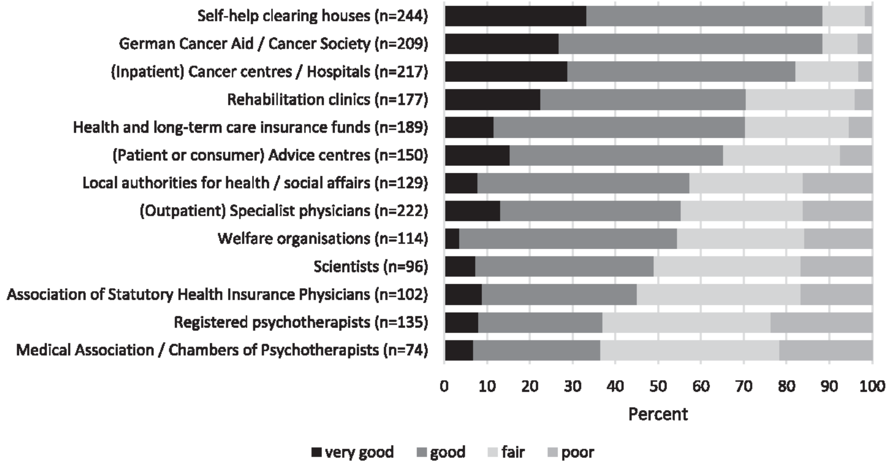

FIGURE 2 Quality of cooperation between self-help groups and care institutions (*N* = 266)

competition (*n* = 22) and ignorance and misconceptions about SHGs (*n* = 22). With regard to the latter, one respondent highlighted 'the general underestimation of the effectiveness of self-help by doctors and clinics'. The hindering factors correspond to the facilitating ones, and overall, most identified themes relate to personnel factors showing that assigned, committed, appreciative and communicative staff with sufficient time enable successful cooperation between cancer care facilities and self-help. The responses thus emphasize the role of human resources rather than formal administrative, spatial or financial factors.

3.1.3 | SHF

With regard to the fulfilment of the SHF quality criteria, over 50% of the respondents perceive 9 out of 10 quality criteria as being fully or rather implemented by the main SHG cooperation partners (Figure 3). The values vary between 52.8% and 86.9%. The quality criterion 'Our SHG is involved in team meetings and/or quality management' is regarded as (rather) fulfilled by only 26.7% of the SHG leaders. Overall the implementation of SHF criteria is rated as 'rather true' (*M* index = 2.7, SD = 0.74, *n* = 259).

3.1.4 | Global satisfaction

In total, 58.1% of the respondents feel well to very well integrated into care facilities. Only 10% of the SHG leaders think their group would be 'poorly' integrated. The mean index indicates good integration of SHGs overall in care facilities (1–4 scale: *M* = 2.7, SD = 0.9, *n* = 260).

3.2 | Bivariate analyses

To assess the correlation between SHF and other variables, we used the SHF scale sum score, which ranges from 0 to a maximum of 10 points. In the calculation of the sum score, we accepted two missing values maximum, which led to valid data from 228 SHG leaders. The average SHF score was 5.9 (SD = 2.4).

Assuming that SHGs who belong to an SHO may be more professionalized and experienced in approaching care facilities for cooperation requests and, thus, may be taken more seriously by hospital staff, we examined the association of the SHF score and membership in an SHO. The association between these is very weak ($\eta = 0.03$). Similarly, we also analyzed the association of the SHF score and the involvement of SHG leaders in the certification process of cancer centres. Here, we found a moderate association of $\eta = 0.23$.

Another assumption underlying the bivariate analyses is that longer existing SHGs may experience a higher quality of cooperation, since successful cooperation may need years of establishing networks and personal relationships to and within cancer care facilities. Yet, across all SHF criteria, the correlation of the SHF score and the age of the group did not support this assumption ($r = .048$, ns). However, when assessing the fulfilment of single SHF criteria and age of the group, weak, but significant positive correlations were found (e.g., SHF criterion 10 'The cooperation with SHGs is fixed in clinical pathways, in the mission statement or similar documentation': $\rho = 0.18$ [$p < .01$], and for SHF criterion 9 'Our SHG is involved in team meetings and/or quality management': $\rho = 0.14$ [$p < .05$]).

About 196 of the SHG leaders stated that being involved in regional health policy decisions would be one of their goals. We assessed whether SHF scores were higher in those SHGs who found this goal to be achieved. The correlation is weak, but significant (Table 3). For some

TABLE 2 Themes and exemplary quotes identified from open-ended responses about successful cooperation

Themes	Subthemes	Respondents	Exemplary quotes
Facilitating factors			
Personal contact person	Contact person, self-help representative; personal communication, personal contact, regular contact, maintaining contact, networking	57	the good personal contact that you have to work for in any case
Mutual appreciation	Appreciation, eye-level contacts, mutual understanding, mutual acceptance and respect, trust; cooperation, willingness, open-mindedness, involvement	52	good cooperation on an equal footing with mutual appreciation
Support of public relations work	Public relations, flyers, (joint) (information) events	37	joint events, flyers and information material to be passed on to those affected
Formal and documented cooperation agreements	Formal and documented cooperation, certifications of the clinics, cooperation agreements	17	drawing up a cooperation agreement, which should then also be lived
Reliable referral	Referral, giving information about SHG	16	that hospitals and practising oncologists specifically point out to affected patients the possibility of participating in self-help groups
Rooms and infrastructure	Infrastructure, premises, proximity of SHG and facility, presentation opportunities	12	rooms available for patient consultations
Participation in quality circles	Quality circles, quality meetings, quality management programmes	8	invitation to the quality circle and similar events of the clinic
Committed facility management	Commitment of individuals, committed doctors	6	if the managers of the respective hospitals are convinced of self-help, and their staff are informed, then real cooperation is possible
Common goals	Common goals, objectives	4	common goals
Sufficient staff	Staff	3	finally sufficient staff in the clinics
Time	Time	3	time
Financial resources	Financial resources	2	financial support
Hindering factors			
Lack of time	Lack of time, overload for SHG and clinic staff; time pressure	41	the limited time of staff due to high patient numbers
Lack of interest	Lack of interest, indifference, ignorance	34	lack of interest in self-help groups
Rejection	Rejection, undesirability, no recognition/appreciation of SHGs, uncooperative behaviour, lack of support	34	if cooperation with the groups is not desired on the part of the hospitals
Lack of contact and communication	Lack of communication, lack of contact	22	no continuous contact
Hierarchy and competition	Competition, hierarchy, arrogance, jurisdictional wrangling	22	blockade and concurrence thinking in the heads of the staff, wrangling over responsibilities
Ignorance	SHG (and its benefits) unknown, inconspicuous, underestimated	21	the general underestimation of the effectiveness of self-help by doctors and clinics
Bureaucratic obstacles	Formalities, administration, requirements for SHGs, non-transparency	14	too much bureaucracy on both sides
Instrumentalisation of the SHG	Cooperation only on paper, exploitation of SHGs for own interests	13	if hospitals only need a support group to become certified

(Continues)

TABLE 2 (Continued)

Themes	Subthemes	Respondents	Exemplary quotes
Data protection	Data protection, laws hindering cooperation	11	data protection often prevents the exchange of data, as there is great uncertainty
Missing or changing contact persons	Missing or changing contact persons	11	lack of contact person
Unreliable referral	Unreliability; no referral to SHGs from the facility	6	no disclosure of information about SHG to the patient
Spatial distance	Distance between SHG and facility	6	long distances between the hospital and the support group
Different objectives	Different goals, views	5	diverging objectives (patient-centred action at the university hospital unfortunately often seems to be just a slogan)
Lack of staff	Lack of staff; overwork of staff	5	too few staff in the hospitals who can take care of these questions and needs of the patients
Lack of financial resources	Economic interests	3	hospitals save where they can

Abbreviation: SHG, self-help group.

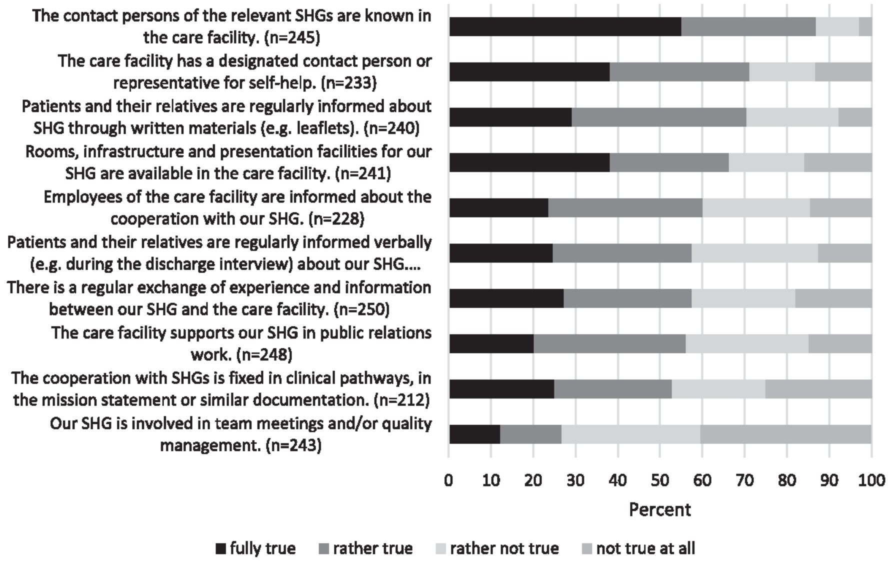

FIGURE 3 Fulfilment of the self-help friendliness criteria ($N = 262$). SHG, self-help group.

individual SHF criteria, however, the correlation is higher (e.g., criterion 9 'Our SHG is involved in team meetings and/or quality management': $\rho = 0.30$; $p < .01$). The SHG goal 'cooperation with professionals' shows a significant moderate positive correlation. The hypothesis, that whenever SHF is high, the referral of patients to the SHGs in cancer care facilities is also common, is supported by a significant moderate correlation. Last, significant moderate to strong correlations exist between the SHF score and the perceived quality of cooperation with cancer care facilities (Table 3).

4 | DISCUSSION

The involvement of patient organizations such as SHGs has become an important goal in health care and health care regulations and is an important measure for the empowerment of cancer patients. Thus, this study assessed the integration of SHGs in cancer care. Our findings based on the experience of 266 leaders of cancer SHGs show that the majority of SHGs cooperate with cancer care facilities and that they rate the quality of the cooperation predominantly

TABLE 3 Correlations between cooperation indicators and self-help friendliness scoring

	Spearman's ρ	p Value
Fulfilment of SHG goal 'involvement in regional health policy decisions'	0.16	<.05
Fulfilment of SHG goal 'cooperation with professionals'	0.28	<.001
Referral to SHG by staff of hospitals and rehabilitation clinics	0.30	<.001
Quality of cooperation with hospitals	0.50	<.001
Quality of cooperation cancer centres	0.33	<.001

Abbreviation: SHG, self-help group.

positive. Yet, there are some significant differences between different cancer care areas. While cooperation with inpatient cancer care units is very common compared to inpatient care units in other indication areas,[27,48] the collaboration between SHGs and registered medical specialists and psychotherapists in ambulatory cancer care needs more attention to strengthen it. These cancer care institutions are also those with which the SHGs cooperate the least. This, on the one hand, may reflect a general low willingness of specialists or psychotherapists in outpatient care to cooperate with SHGs. On the other hand, the low-rated quality of cooperation with these institutions could stem from the prejudice of the SHG leaders towards these professionals, and the perceived lack of will for cooperation may have influenced the rating of the quality of cooperation. A further reason for the lack of cooperation might stem from the fact that most registered physicians—in any case, the general practitioners—and psychotherapists do not only treat patients with cancer but a range of other diseases, too. Therefore, care for cancer patients is just one focus among others, and it may neither be feasible nor appropriate to integrate cancer SHGs as just one of several other disease-related SHGs into their everyday practice.

The satisfying results for SHF in inpatient cancer care may not be very surprising insofar as many cancer centres in Germany are certified by the German Cancer Society. In parallel, the German Comprehensive Cancer Centres which are funded by the German Cancer Aid and take on specialized research on the development of therapies in addition to providing quality care, are similarly audited and certified by the German Cancer Aid. These certificates require measures for systematic cooperation with SHGs. Still, the findings demonstrate the need for further improvement concerning the referrals to SHGs. It is noteworthy that according to our findings, significantly more patients go to a support group on the recommendation of persons within their private and social environment than on the recommendation of hospital staff. Those findings are in line with international studies that found low referral rates from cancer nurses and physicians in hospitals despite positive attitudes toward SHGs.[38–40] Information and recommendations are often irregular and depend on the personal characteristics of individual nurses and physicians, but of course also on those of the patients themselves. SHGs are not suggested to all patients equally, and the potential needs for peer support are subjectively assessed by clinicians and therefore often misjudged.[16,38] Similarly, in open-ended questions of this study the respondents stressed the importance of reliable referral of patients into the groups as an indicator of successful cooperation. Implementing the concept of SHF would help to standardize the communication on peer support and SHGs. All patients would then at least have the chance to think about an SHG visit or a chat with a peer counsellor.

Reasons for low referrals certainly lay in the changing health care systems. Due to financial pressures and higher caseloads of patients[29] in less time, physicians talk less to the patients and therefore the latter ones may look elsewhere for information.[15] This perception is supported by the respondents as well, naming limited time of staff due to high numbers of patients and lack of interest of the care facilities' staff as the main hindering factors for the cooperation between SHGs and cancer care facilities. Previous studies also reported not having enough time and forgetfulness as the most common barriers from clinicians to referral to peer support.[39,49] Further practical barriers seem to be lack of visibility of SHGs and referral materials on hand,[38,49] which was also named by respondents, who wished for more support in public relations work such as the use of their pamphlets or information flyers. The need for effective 'marketing' of SHGs was demonstrated in a study by Garrett et al.[41] as well. However, low referral rates need not always be due to the care facilities. Many patients are overwhelmed by the information they receive in the hospital[49] and do not join SHGs right after treatment but later on. Therefore, in the information overload, important information about SHGs may not be picked up by patients or may be quickly forgotten, and cancer care staff may not be sure whether or not to provide additional information about SHGs.

Another hindering factor to the integration of SHGs mentioned by respondents in this study was the perceived lack of appreciation of SHGs and the underestimation of the effectiveness of SHGs. This attitude may stem from clinicians' and nurses' concerns about biased or misinformation being shared in SHGs, and the persistence of such concerns has been shown in various studies.[38,40,50] Common misconceptions about SHGs relate to the lack of knowledge about the level of professionalism of the organization of SHGs.[38,41]

The lack of cooperation between hospitals and SHGs may further be due to unclear distribution of tasks among hospital staff and lack of standardized processes regarding referrals, as pointed out by Legg et al.[42] This is supported by a study demonstrating that although peer support is approved, it is not necessarily perceived as part of nurses' work.[38] SHG leaders on the other hand are also aware of this gap and named personal contact persons, key persons and regular exchange as facilitating factors for the cooperation between SHG and cancer care facilities. It is worth emphasizing that these expressed needs are completely in line with the quality indicators for SHF.

With regard to the fulfilment of the SHF quality criteria, the results demonstrate that they are generally implemented quite well with the exception of participation in internal processes. Here, the integration of SHGs seems to be a bigger challenge as reflected by the lack of involvement of SHGs in team meetings or quality management features of the facilities. This finding may indicate a tendency that some facilities may cooperate to a certain extent with SHGs. Including SHGs as part of their own team, however, might go too far, and they still perceive them as external, which, in fact, may not be appropriate. Kallio et al.[38] similarly reported that hospital staff tends to be passive in their support of peer support outside their own hospital. This could be due to competition thoughts and misconceptions about SHGs from facilities' staff as named in the open-ended questions. Yoshikawa et al.[50] further demonstrated the ongoing perception of SHGs presenting a kind of threat or competitor to cancer care professionals. Here, SHF seems to benefit from long-established groups and relationships as suggested by the results of the bivariate analyses. Yet, the results indicate good overall integration of SHGs in cancer care, even for institutions that do not necessarily use the concept of SHF explicitly for it.

Though the findings provide some evidence for how well SHGs are integrated into cancer care, there are several limitations of the study that need to be acknowledged. First, due to the recruitment mode, the study is not representative, and there may be a bias in favour of positive reporting. Although nearly 60% of the SHG leaders feel well or very well integrated into cancer care facilities and SHF criteria are mostly implemented, these results could represent an overestimation due to selection bias since most respondents are SHG leaders of well-established SHOs belonging to the umbrella organization HCSH. Further, half of the SHG leaders are involved in the certification processes of cancer care units. This suggests that these groups are already acting on a higher formalized level. Besides, the results only represent the experience and perceptions of SHG leaders and might differ from those of ordinary group members. An interesting avenue for future studies would be to map the perspective of the professionals equally, by using the SHF scale in both the patient version and the hospital staff version at the same time.

5 | CONCLUSION

SHF is a feasible measure to operationalize the integration of SHGs and to meet the increased demand for patient involvement in cancer care. The findings show a positive assessment of the involvement of self-help in oncological care from the view of SHG representatives. The majority of the inpatient care facilities with which the SHG leaders cooperate fulfil most of the SHF quality criteria. This corresponds to the SHG leaders' satisfaction with cooperation and integration. With regard to referral processes, information about SHGs should be more established in oncological care, specifically in outpatient care.

As SHF represents not only a number of criteria for patient involvement but also a whole participatory developed and evaluated concept, managers and staff of health care facilities should consider a possible implementation.

AUTHOR CONTRIBUTIONS

Elâ Ziegler, Jens Klein and Christopher Kofahl designed and directed the study. Elâ Ziegler, Christopher Kofahl, Stefan Nickel and Alf Trojan developed the main conceptual ideas and the outline. Elâ Ziegler and Christopher Kofahl performed the measurements. Stefan Nickel, Alf Trojan and Jens Klein were involved in planning the work. Elâ Ziegler drafted the manuscript with help of Christopher Kofahl and input from all authors. Christopher Kofahl supervised the work. Christopher Kofahl, Jens Klein, Stefan Nickel and Alf Trojan aided in interpreting the results and worked on the manuscript. All authors commented on, contributed to and approved the final manuscript.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Derived data supporting the findings of the study are available from the corresponding author on request.

ETHICS STATEMENT

The ethical approval for the study was obtained from the Local Psychological Ethics Committee at the Centre for Psychosocial Medicine of The University Medical Centre (reference number LPEK-0066).

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APPENDIX

Questionnaire on implementation of self-help friendliness criteria

Scaling: fully true – rather true – rather not true – not true at all – do not know

Rooms, infrastructure, and presentation facilities for our self-help group (SHG) are available in the care facility.

Patients and their relatives are regularly informed verbally (e.g., during the discharge interview) about the possibility of participating in our SHG.

Patients and their relatives are regularly informed about the possibility of participating in an SHG through written materials (e.g., leaflets).

The care facility supports our SHG in public relations work.

The care facility has a designated contact person or representative for self-help.

The contact persons of the relevant SHGs are known in the care facility.

There is a regular exchange of experience and information between our SHG and the care facility.

Staff of the care facility are informed about the cooperation with our SHG.

Our SHG is involved in team meetings and/or quality management.

The cooperation with SHGs is fixed in clinical pathways, in the mission statement or similar documentation.

9. Summary

Peer support has become an important pillar in cancer care. For many cancer patients, cancer peer support groups offer a resource outside the professional psychosocial care to provide informational and emotional support. However, it has not yet been sufficiently investigated how cancer peer support groups contribute to patients' empowerment and to what extent peer support groups are integrated into the oncological care system. Therefore, this cumulative dissertation consisting of four publications examines the integration of cancer peer support in routine care and assesses its association with psychological empowerment of cancer patients. To address these questions, an exploratory sequential mixed-methods design was carried out that comprises two major phases of research: phase I focuses on the experiences of cancer support group leaders, while phase II is directed at cancer patients and their experiences. The qualitative phase included interviews with 11 peer support representatives that were analysed thematically and served for the instrument development of the quantitative phase. A systematic literature search was simultaneously deployed to investigate the impact of peer support on empowerment. Zooming into the interactional component of psychological empowerment, cancer-related knowledge was then measured and compared between members and non-members of cancer peer support groups through t-tests and multiple linear regression. To enable this, a new participatory developed instrument was used in a cross-sectional survey with 1,121 cancer patients in Germany. Lastly, to assess the integration of peer support in cancer care, a cross-sectional survey with 266 cancer peer support group leaders was conducted and data analysis involved univariate and bivariate statistics.

The systematic review of 29 included studies showed participation in peer support to be positively associated with the three components of psychological empowerment and revealed a small to moderate effect. Knowledge was identified as a central dimension of the studies as well as a lack of objective instruments to measure knowledge across different cancer entities. For instrument development, the qualitative interviews revealed diagnosis, treatment and (social) legal issues as central for cancer-related knowledge and were incorporated into the new Brief Cancer Knowledge Scale (BCKS). The BCKS was developed as a 14-item instrument and showed good psychometric properties. It was tested in a sample of cancer patients and showed peer support group members having significantly higher knowledge than non-members, but also high variance among all cancer patients. Peer support group membership was the third most decisive independent factor contributing to higher cancer-specific knowledge among education, internet use, age and gender. The survey with peer support group leaders found a positive assessment of the integration of peer support in care, but also differences between inpatient and outpatient care facilities, and low referrals. The quantitative evidence of the identified international literature and the conducted studies suggests participation in peer support programmes can promote patients' empowerment, i.e. through cancer knowledge, which can be measured using the brief BCKS. Due to these findings and the identified lack of systematic integration of peer support across cancer care facilities, peer support in routine care should be promoted and integrated further for comprehensive, (cost-)effective oncological care for all patients nationwide. This can be achieved through additional resources such as central contact persons for patients, integrated pathways in care facilities and the concept of self-help friendliness. Thus, the findings can contribute to improvements in cancer care and increase patient-centred care.

9. Zusammenfassung

Die gemeinschaftliche Selbsthilfe ist zu einer wichtigen Säule der Krebsversorgung geworden. Für viele Krebspatient:innen stellen Krebs-Selbsthilfegruppen eine Ressource außerhalb der professionellen psychosozialen Betreuung dar, die ihnen Informationen und emotionale Unterstützung bietet. Es ist jedoch noch nicht ausreichend erforscht, wie Krebs-Selbsthilfegruppen zum Empowerment von

Patient:innen beitragen und inwieweit sie in das onkologische Versorgungssystem integriert sind. Daher wird in dieser kumulativen Dissertation bestehend aus vier Publikationen die Integration von Krebs-Selbsthilfegruppen in die Routineversorgung untersucht und ihr Zusammenhang mit dem psychologischen Empowerment von Krebspatient:innen beurteilt. Zur Beantwortung dieser Fragen wurde ein exploratives sequentielles Mixed-Methods-Design durchgeführt, das zwei Hauptforschungsphasen umfasst: Phase I konzentriert sich auf die Erfahrungen von Leiter:innen von Krebs-Selbsthilfegruppen, während sich Phase II an Krebspatient:innen und deren Erfahrungen richtet. Die qualitative Phase umfasste Interviews mit 11 Selbsthilfe-Vertreter:innen, die thematisch ausgewertet wurden und der Instrumentenentwicklung der quantitativen Phase dienten. Gleichzeitig wurde eine systematische Literaturrecherche durchgeführt, um die Wirkungen der Krebs-Selbsthilfe auf das Empowerment zu untersuchen. Mit Blick auf die interaktionelle Komponente des psychologischen Empowerments wurde schließlich das krebsbezogene Wissen gemessen und mittels t-Tests und multipler linearer Regression zwischen Mitgliedern und Nicht-Mitgliedern von Krebs-Selbsthilfegruppen verglichen. Dazu wurde ein neues partizipativ entwickeltes Instrument in einer Querschnittsbefragung mit 1.121 Krebspatienten in Deutschland eingesetzt. Letztlich wurde zur Bewertung der Integration von Selbsthilfe in die Krebsversorgung eine Querschnittsbefragung mit 266 Leiter:innen von Krebs-Selbsthilfegruppen durchgeführt und die Datenanalyse erfolgte mittels univariater und bivariater Statistiken.

Die systematische Übersichtsarbeit von 29 eingeschlossenen Studien ergab, dass die Teilnahme an Krebs-Selbsthilfe positiv mit den drei Komponenten des psychologischen Empowerments assoziiert ist und kleine bis moderate Effekte aufweist. Wissen wurde als eine zentrale Dimension der Studien identifiziert, ebenso wie ein Mangel an objektiven Instrumenten zur Messung von Wissen über verschiedene Krebsentitäten hinweg. Für die Instrumentenentwicklung ergaben die qualitativen Interviews, dass Diagnose, Behandlung und (sozial-)rechtliche Fragen von zentraler Bedeutung für krebsbezogenes Wissen sind und wurden in die neue Brief Cancer Knowledge Skala (BCKS) integriert. Der BCKS wurde als 14-Item-Instrument entwickelt und zeigte gute psychometrische Eigenschaften. Er wurde in einer Stichprobe von Krebspatient:innen getestet und zeigte, dass Mitglieder von Selbsthilfegruppen ein signifikant höheres Wissen haben als Nicht-Mitglieder, aber auch eine hohe Varianz unter allen Krebspatient:innen. Die Mitgliedschaft in einer Selbsthilfegruppe war der drittwichtigste unabhängige Faktor, der zu einem höheren krebsspezifischen Wissen beitrug, nach Bildung und Internetnutzung, vor Alter und Geschlecht. Die Befragung von Krebs-Selbsthilfe-Gruppenleiter:innen ergab eine positive Bewertung der Integration von Selbsthilfe in die Versorgung, aber auch Unterschiede zwischen stationären und ambulanten Versorgungseinrichtungen und geringe Vermittlungen. Die quantitative Evidenz der identifizierten internationalen Literatur und der durchgeführten Studien deutet darauf hin, dass die Teilnahme an Selbsthilfe-Programmen das Empowerment der Patient:innen fördern kann, z. B. durch Krebswissen, das mit dem BCKS gemessen werden kann. Aufgrund dieser Ergebnisse und des festgestellten Mangels an systematischer Integration von Selbsthilfe in Einrichtungen der Krebsversorgung, sollte Selbsthilfe in der Routineversorgung gefördert und weiter integriert werden, um eine umfassende, (kosten-)effektive onkologische Versorgung für alle Patient:innen bundesweit zu gewährleisten. Dies kann durch zusätzliche Ressourcen wie zentrale Ansprechpersonen für Patient:innen, integrierte Versorgungspfade in Einrichtungen und das Konzept der Selbsthilfefreundlichkeit erreicht werden. Somit können die Ergebnisse zu einer Verbesserung der Krebsversorgung beitragen und die patient:innenzentrierte Versorgung stärken.

10. Declaration of own contribution to publications

Publications 1, 3 and 4 were completed with sole first authorship by me. For publication 2 I had last authorship. My contribution to the four publications relevant to this dissertation is described in more detail below.

Publication 1) Empowerment in cancer patients: Does peer support make a difference? A systematic review

I developed the article outline and the literature search terms in consultation with Prof Dr Olaf von dem Knesebeck and Dr Christopher Kofahl. In cooperation with Berit Lieske and Josephine Nana Hill, I organised, screened and rated the identified articles and interpreted the data. I drafted the manuscript with critical remarks from all co-authors. I formatted and finalised the manuscript and submitted it to the designated journal. The peer-reviewed revisions and re-submissions were done by me after discussions with my co-authors.

Publication 2) Development and psychometric properties of a brief generic cancer knowledge scale for patients (BCKS-10)

The study and manuscript conception was jointly realised by the three authors. I conducted and analysed the expert interviews, carried out extensive literature search and developed the BCKS instrument. I finalised the instrument with input from Dr Jens Klein and Dr Christopher Kofahl. In consultation with the co-authors, I developed the surveys among patients and peer leaders. I prepared the dataset and variables for the analyses. I helped Dr Jens Klein interpret the data, to draft and finalise the manuscript with critical revisions and remarks. I was involved in revising the manuscript and preparing it for re-submission after peer review.

Publication 3) Do members of cancer peer support groups know more about cancer than non-members? Results from a cross-sectional study in Germany

Along with both co-authors, I was responsible for designing and conducting the study and collecting data. I solely carried out the literature search and data analyses and interpreted the data. I developed the article outline and wrote the manuscript with remarks by the two co-authors. I finalised the manuscript and handled the submission, re-submission and communication within the peer-review process of the journal. After receiving the reviewers' comments, I revised the manuscript accordingly and performed further data analyses.

Publication 4) Self-help friendliness in cancer care: A cross-sectional study among self-help group leaders in Germany

Study design and direction were done by Dr Christopher Kofahl, Dr Jens Klein and me. The manuscript outline was developed by me after consultation with Dr Christopher Kofahl, Prof Dr Alf Trojan and Dr Stefan Nickel. I performed the statistical analyses with support from Dr Christopher Kofahl. I wrote the manuscript taking into account suggestions for changes made by all co-authors. I finalised, formatted and submitted the manuscript to the designated journal. I incorporated the reviewers' comments into the manuscript and was responsible for re-submission.

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Finally, to my husband, my family and friends I would like to express my deepest gratitude for your love and always believing in me, standing by my side always and giving me strength to never give up. I am forever grateful to you.

12. Curriculum vitae

Lebenslauf entfällt aus datenschutzrechtlichen Gründen.

13. Affidavit (Eidesstattliche Erklärung)

Ich versichere ausdrücklich, dass ich die Arbeit selbständig und ohne fremde Hilfe verfasst, andere als die von mir angegebenen Quellen und Hilfsmittel nicht benutzt und die aus den benutzten Werken wörtlich oder inhaltlich entnommenen Stellen einzeln nach Ausgabe (Auflage und Jahr des Erscheinens), Band und Seite des benutzten Werkes kenntlich gemacht habe.

Ferner versichere ich, dass ich die Dissertation bisher nicht einem Fachvertreter an einer anderen Hochschule zur Überprüfung vorgelegt oder mich anderweitig um Zulassung zur Promotion beworben habe.

Ich erkläre mich einverstanden, dass meine Dissertation vom Dekanat der Medizinischen Fakultät mit einer gängigen Software zur Erkennung von Plagiaten überprüft werden kann.

Hamburg, den 12.06.2023

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Elâ Ziegler