Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ) xxx (2017) xxx–xxx

Contents lists available at ScienceDirect

Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ)

journal homepage: http://www.elsevier.com/locate/zefq

Beteiligung von Patientinnen und Patienten / Patient Participation

Patient involvement in a systematic review: Development and pilot evaluation of a patient workshop

Beteiligung von Patienten an einem systematischen Review: Entwicklung und Pilotevaluation eines Patientenworkshops

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ARTICLE INFO

Article History:
Received: 9 November 2016
Received in revised form: 7 July 2017
Accepted: 14 July 2017
Available online: xxx

Keywords:
patient involvement
patient participation
consumer participation
systematic review
meta-analysis

ABSTRACT

Patient involvement (PI) in research is increasingly required as a means to improve relevance and meaningfulness of research results. PI has been widely promoted by the *National Institute for Health Research* in England in the last years. In Germany, widespread involvement of patients in research is still missing. The methods used to realize PI have been developed mainly in English research contexts, and detailed information on how to involve patients in systematic reviews is rare. Therefore, the aim of the study was that patients contribute and prioritize clinically relevant outcomes to a systematic review on meta-cognitive interventions, and to evaluate a patient workshop as well as patients' perceptions of research involvement. Seven patients with experience in psychiatric care participated in our workshop. They focused on outcomes pre-defined in the review protocol (e.g., meta-cognitive or cognitive changes, symptomatology, quality of life), neglected other outcomes (like satisfaction with treatment, acceptability), and added relevant new ones (e.g., scope of action/autonomy, applicability). Altogether, they valued the explicit workshop participation positively. However, some suggested to involve patients at an earlier stage and to adapt the amount of information given. Further systematic reviews would benefit from the involvement of patients in the definition of other components of the review question (like patients or interventions), in the interpretation of key findings or in drafting a lay summary.

ARTIKEL INFO

Artikel-Historie:
Eingegangen: 9. November 2016
Revision eingegangen: 7. Juli 2017
Akzeptiert: 14. Juli 2017
Online gestellt: xxx

Schlüsselwörter:
Patientenbeteiligung
Partizipation
systematischer Review
Metaanalyse

ZUSAMMENFASSUNG

Die Beteiligung von Patientinnen und Patienten in der Forschung wird zunehmend gefordert, um die Relevanz und Aussagefähigkeit von Forschungsergebnissen zu verbessern. Während das *National Institute for Health Research* in England die Patientenbeteiligung seit Jahren fördert, fehlt es in Deutschland noch weitgehend an flächendeckender Forschungsbeteiligung. Zudem liegen Informationen über Methoden der Patientenbeteiligung hauptsächlich für englische Forschungskontexte vor, und detaillierte Informationen zur Patientenbeteiligung in systematischen Reviews sind lückenhaft. Das Ziel der Studie war es daher, dass Patienten klinisch relevante Zielgrößen zu einem systematischen Review zu metakognitiven Interventionen beitragen und priorisieren und dass sie einen Patientenworkshop und ihre wahrgenommene Forschungsbeteiligung bewerten. Sieben psychiatrieerfahrene Patienten nahmen an unserem Workshop teil. Sie benannten Zielgrößen, die im Reviewprotokoll schon vorgesehen waren (z.B. metakognitive und kognitive Veränderungen, Symptomatik, Lebensqualität), vernachlässigten andere Endpunkte (z.B. Zufriedenheit, Akzeptanz) und fügten neue Zielgrößen hinzu (z.B. Handlungsspielräume/Autonomie,

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http://dx.doi.org/10.1016/j.zefq.2017.07.005
1865-9217/

Please cite this article in press as: Brütt AL, et al. Patient involvement in a systematic review: Development and pilot evaluation of a patient workshop. Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ) (2017), http://dx.doi.org/10.1016/j.zefq.2017.07.005

Anwendbarkeit). Die Patienten würdigten die Workshopteilnahme insgesamt. Einige empfahlen jedoch eine frühere Beteiligung und eine Anpassung der gegebenen Informationen. Zukünftige systematische Reviews können von der Beteiligung von Patienten bei der Definition weiterer Bestandteile der Fragestellung (wie Population oder Interventionen), der Interpretation zentraler Ergebnisse oder der Formulierung einer allgemeinverständlichen Zusammenfassung profitieren.

Introduction

Patient-centered health research denotes research that is informed by the perspectives, interests and values of patients. It is assumed that patient-centered health research leads to findings and focuses on outcomes that highly matter to patients thereby reducing clinical uncertainty, accelerating adoption of meaningful findings and improving health outcomes [1–3]. Becoming involved in health research implies that patients act as partners with valuable expertise, perspectives, and insights. Even in 1969, Arnstein conceptualized public participation on a ladder-model with ascending levels of power and control [4]. Only the upper levels of partnership, delegated power and citizen control are regarded as facilitating true partnership possibilities [4,5], which is important to consider in patient involvement as well. Although sometimes used interchangeably [6], we distinguish public involvement, which refers to involvement of members of the public or via patient groups or organizations, from patient involvement (PI) as the participation of users or patients based on their individual experience with a disease or with specific health interventions [5].

PI can be implemented in a wide array of fields [5], in original research as well as in conducting systematic reviews. Whereas PI in original research may deal with developing research materials or recruiting and interviewing research participants, PI in systematic reviews focuses on identifying and prioritizing topics, developing the protocol, conducting the review, and disseminating the results [7]. For ensuring that reviews reflect the needs and priorities of patients, PI has become an important principle in evidence-based practice, e.g., in reviews conducted with the Cochrane Collaboration. PI can range from involvement on a programmatic level in the organization, or in individual reviews through one-time or continuous collaboration [6,7]. Whereas PI in writing lay summaries has been widely implemented, the extent of PI in further processes is varying considerably [7,8]. General principles of successful PI in research have been set up [9]. Nonetheless, consented methods on how patients can act effectively as part of the review team are missing. Recently, recommendations for involving patients in meta-syntheses have been published [10]. So far, the *National Institute for Health Research* [6] summarizes case examples on involving patients at the individual and programmatic level, and also other organizations published principles or procedures for PI [11–14]. Moreover, first evaluations of PI in systematic reviews and meta-analyses have been published. Vale and colleagues [15] conducted a meta-analysis in cervical cancer treatment. They established an advisory group with six women having received treatment for cervical cancer. Six meetings took place throughout the course of the project and patients were involved by providing feedback on information material, contributing to newsletters, and providing feedback into the lay summary. Overall, PI was regarded as a positive experience for both researchers and patients [15]. In their systematic review relating to physiotherapy after stroke, Pollock and colleagues [16] formed a stakeholder group consisting of stroke survivors, carers and physiotherapists. In three meetings, the stakeholder group gave feedback on categorizing interventions, defining treatment components and deducing main conclusions from the review. The group actually had a substantial impact on the review especially regarding the categorization of treatments [16]. So far, information on how to implement PI is predominantly available in English research contexts. Strategies that have been successfully implemented in Germany are rarely available. Moreover, detailed information on how to involve patients in systematic reviews is missing.

Therefore, we focused on how patients could be meaningfully involved in our systematic review to complete the review protocol. The aims of the present study were a) that patients contribute and prioritize clinically relevant outcomes of meta-cognitive interventions, and b) that they evaluate a patient workshop and give their perceptions of research involvement.

Methods

Design and setting

In order to combine qualitative with quantitative data, a mixed method design involving a focus group discussion and a cross-sectional survey with a subsequent prioritization task was chosen. The current pilot evaluation was part of a larger systematic review on metacognitive interventions [study title “Effectiveness of metacognitive interventions for mental disorders in adults: a systematic review (METACOG)”, registered with the International Prospective Register of Systematic Reviews (PROSPERO), Protocol No. CRD42016051006]. Detailed study information is available from the review protocol [17]. Metacognitive interventions specifically focus on the role of maladaptive cognitive processes, as opposed to cognitive contents, in the development, maintenance and treatment of mental disorders. Some mainly involve psychological interventions focusing on cognitive processes and related dysfunctional beliefs (e.g., thought suppression and beliefs about its effect in “metacognitive therapy” [18]) whereas others highlight specific cognitive biases (e.g., jumping to conclusions in “metacognitive training” [19,20]).

Workshop development and content

For workshop preparation we referred to available recommendations for PI [6,10,15,16]. The workshop included information regarding systematic reviews and meta-analyses in the context of evidence-based medicine. Thereby, we extended a research training developed for patients with mental disorders [21]. Further, the METACOG project and background information concerning metacognitive interventions were presented. Power Point slides and a number of illustrations were used to provide information. Questions and feedbacks were integrated to promote PI and verify comprehension. The three-hour workshop was conducted by two postdoctoral researchers experienced in patient involvement (ALB) and systematic reviews (FK) in December 2015 at the Department of Medical Psychology.

Additionally, participants received a detailed written guide covering patient-related information on health services research and evidence-based medicine (e.g., study designs, evidence grades), systematic reviews and meta-analyses (e.g., steps in a meta-analysis), a description of the current study on metacognitive interventions, information relevant to involvement in research (e.g., definition of the term “clinically relevant outcome”) and a glossary (e.g., randomized-controlled trial, treatment as usual). The

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