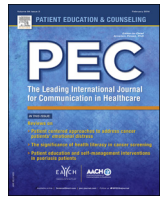




Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Research Paper

How participatory action research changed our view of the challenges of shared decision-making training

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ARTICLE INFO

Article history:

Received 21 April 2017

Received in revised form 2 November 2017

Accepted 3 November 2017

Keywords:

Communication skills training

Shared decision-making

Existential communication

Participatory action research

Patient involvement

Theatre workshop

ABSTRACT

Objective: This paper aims to demonstrate how the use of participatory action research (PAR) helped us identify ways to respond to communication challenges associated with shared decision-making (SDM) training.

Methods: Patients, relatives, researchers, and health professionals were involved in a PAR process that included: (1) two theatre workshops, (2) a pilot study of an SDM training module involving questionnaires and evaluation meetings, and (3) three reflection workshops.

Results: The PAR process revealed that health professionals often struggled with addressing existential issues such as concerns about life, relationships, meaning, and ability to lead responsive dialogue. Following the PAR process, a communication programme that included communication on existential issues and coaching was drafted.

Conclusion: By involving multiple stakeholders in a comprehensive PAR process, valuable communication skills addressing a broader understanding of SDM were identified. A communication programme aimed to enhance skills in a mindful and responsive clinical dialogue on the expectations, values, and hopes of patients and their relatives was drafted.

Practical implications: Before integrating new communication concepts such as SDM in communication training, research methods such as PAR can be used to improve understanding and identify the needs and priorities of both patients and health professionals.

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1. Introduction

The increased emphasis on patient involvement in clinical decisions has led to a growing volume of research regarding shared decision-making (SDM). In particular, much attention has been focused on the “information exchange” component of SDM [1], and the literature describes decision aids as tools to help patients

understand the risks and benefits of screening, examinations, and treatments. However, decision aids are not meant to replace dialogue between patients, relatives, and clinicians, but rather to complement it. The inclusion of complex information and the usage of decision aids require improved communication skills in health professionals [1–4]. As a consequence, ready-made programmes for training health professionals in SDM are in high demand, and the production of training programmes is growing quickly worldwide. Nonetheless, these training programmes vary widely, few are formally evaluated [5,6], and several related studies in clinical practice are drawing attention to the complex communication skills needed in SDM [5,7–17].

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Many patients are not accustomed to being involved in treatment plans and therefore might possess more traditional expectations regarding their individual role and the role of the clinician [8–11]. Patients are often unaware that there are choices to be made, and indeed when patients are aware, they may not necessarily want to be involved in the decision-making process [7]. Recently, following the observation that clinicians seem to have difficulty handling SDM, several papers have focused on the emotional and relational dimensions of care in the information-intensive SDM process. The inherent uncertainty and vulnerability of the process elicits emotional, relational, spiritual, and existential issues [13,14,18,19]. Here, spiritual and existential issues are understood as concerns of life, relationships, and meaning [20,21]. Coping with clinical uncertainty can be challenging for health professionals [22]. Clinicians often try to avoid addressing existential dimensions in clinical encounters [23,24], citing lack of time, education, and spiritual self-awareness as key reasons [24–26]. Considering these additional challenges, health professionals' training in SDM could possibly need a broader approach than a focus on information exchange to effectively support patients.

At Lillebaelt Hospital in Denmark, all health professionals have participated in a basic communication course based on the Calgary-Cambridge Guide (CC-guide) [27–29]. However, further competency to support patients in their decision-making has been requested by both staff and management. This need was also reflected by the patients' experiences in the Danish National Survey of Patients, which showed that involvement in decisions was among the lowest-rated items, although the ratings at Lillebaelt Hospital were above the national average [30]. Therefore, we started to develop an SDM training programme strongly influenced by traditional SDM training. However, at the same time, we recognised that a new view of SDM was emerging that might require both upgraded communication skills and a cultural change among professionals, patients, and the hospital organisation [12]; hence, we decided to use participatory action research (PAR) in order to engage stakeholders and possibly generate knowledge that could be used in the development of new training programmes [31]. Although SDM has primarily been associated with physicians' work, we decided that the training programmes should also target nurses and other health professionals involved in clinical decision-making.

This paper aims to demonstrate how the use of PAR helped us identify ways to respond to training challenges involved in SDM as part of a larger enterprise to change our hospital's communication culture.

2. Methods

2.1. Participatory action research

Acknowledging that effective public health requires methodological pluralism, PAR has been increasingly used in health care research over the last few decades [32–34]. It draws on the paradigms of critical theory and constructivism [35] and as a methodology refers to how research is done and how knowledge is gained using broad range of qualitative and quantitative methods [36].

In contrast to positivist science in which the world is regarded as a single reality that can be observed and measured objectively, PAR scientists posit that the observers bring to their inquiry a set of values that will influence the study observations. Furthermore, they advocate that those being observed are also actively involved in the research process [37,38].

PAR (also referred to as just “action research”) is one of the many endeavours to operationalising participatory research and action research [39–41]. The distinction between the terms and the inquiry methods used can be both vague and contradictory, but although they differ along ideological and procedural dimensions, the different approaches share broadly similar features [25,41].

Like other action research strategies, PAR deals with practical real-world problems and issues, change-focused outcomes, the involvement of cyclical processes and feedback loops, the personal involvement of the researcher and the observed participants, an emancipatory agenda, and a critical inquiry into and opposition to established policies and practices [40]. PAR has been defined as:

“A participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.” [31]

In the systematic cycles of actions, the stakeholders provide knowledge through different activities. In the reflection stages, lived experiences are transformed into knowledge and sense-making in collaborative dialogues with stakeholders and the research team [42]. The activities used to provide knowledge and reflection in this study included: [1] theatre workshops, [2] a pilot study of an SDM training module, and [3] reflection workshops. PAR must not be confused with the much-used quality-improvement cycle Plan-Do-Study-Act, which is built on a positivist paradigm [43].

Table 1

An overview of the participants included in main activities used to provide knowledge and reflection in the PAR process.

Activities	Participants	Approx. number of participants in each activities ^a
Theatre workshops [2]	Patients and relatives Communication trainers Health professionals Researchers Collaborators	90
SDM courses for trainers [2]	Communication trainers (doctors and nurses)	15
SDM courses for trainees [6]	Doctors and nurses from the department of oncology	48
Evaluation meetings [3]	Communication trainers Researchers	22
Reflection meetings [3]	Researchers affiliated with our research unit Collaborators related to research in health communication	30

^a Some of the participants participated in more than one activity.

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