

How Participatory Action Research Changed Our View of the Challenges of Shared Decision-Making Training

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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.

Keywords: communication skills training; shared decision-making; existential communication; participatory action research; patient involvement; theatre workshop

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).

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-intense 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).

2.2. Setting

The study was conducted at Lillebaelt Hospital, a regional hospital consisting of 18 clinical departments and 10 clinical service departments. The hospital's total number of employees is approximately 4,800, with 3,000 working in clinical departments. In connection with the training programme, Clear Cut Communication with Patients, 90 health professionals were trained to become communication trainers (28, 29). The present study is based on this programme and constitutes the second phase of the hospital's communication project.

2.3. Participants

Table 1 outlines the groups that participated in the activities that constitute the PAR process. Invitations to participate in the theatre workshops were sent to health professionals from the hospital, researchers within the patient communication field, and the hospital's Patient and Relatives Council. Seven trainers, doctors, and nurses from the department of oncology participated in the development and testing of the SDM course. For the second train-the-trainer course, participants were recruited from the entire group of communication trainers at the hospital using email invitations.

2.4. Cycles of actions and reflections

The cycles of actions and reflections were an iterative process where each of the activities was linked together by sharing data, analysis, and results. The process is illustrated in Figure 1 and the timeline for the activities in Table 2. In the following sections, we describe the methods used to facilitate this process. As reflection and knowledge are regarded as outcomes of a PAR process, these components are reported in the Results section.

2.4.1. Developing and testing an SDM training course

The first edition of a one-day course was developed and tested by six of this study's authors (AN, PG, ML, KDS, LHJ, and JA). Figure 2 illustrates the process for testing and adjusting the course programme. The course was based on the SDM model developed by Elwyn et al. (44) that targets doctors and nurses from clinical departments and uses role-playing and video recordings as the main pedagogical tools (28). The main purposes of the course were to develop new knowledge and to teach skills related to: (1) the identification and visibility of the decision; (2)

clarification of roles and preferences in relation to SDM; (3) giving information about possibilities, advantages, and disadvantages; and (4) facilitating a dialogue about expectations, values, concerns, and hopes. As a part of the testing, two courses for communication trainers were conducted, and at the department of oncology, the trainers subsequently trained the doctors and nurses. During the process, three evaluation meetings with the trainers were conducted, and questionnaires developed for the purpose were completed by the trainees after the course (Figure 2).

2.4.2. Theatre workshop

Based on experiences in using improvisational theatre as an interactive method to facilitate cultural change (45), we used theatre workshops to explore situations where complex clinical decisions occur. In the two theatre workshops, patients and relatives were present in the morning sessions, and the afternoon sessions were solely for health professionals and researchers as we chose to focus on the personal challenges of the health professionals and on supervision; however, this session was still based on the problems identified in the morning.

Cases from clinical practice were performed by professional actors and used as the basis for group activities and plenary discussions. As part of this process, the participants were encouraged to contribute their ideas regarding alternative ways to “act the scene” and selected suggestions were explored by inviting the proposer onto the stage, or by asking the actors to re-perform the scene in a different way (46). Each workshop lasted seven hours and was facilitated by one of the authors (HL). All of the theatre workshops were videotaped.

2.4.3. Reflection workshops

In-between the activities, we used reflection workshops as a method to analyse our findings (41) by discussing decision-making based upon experiences theretofore, including relationships to key concepts of care and existential dimensions. The purpose of each reflective workshop was to (1) debrief the preceding activities, (2) discuss feelings and thoughts, (3) discuss the next step, and (4) discuss other possibilities or ideas (47). As preparation for our discussion, we used studies addressing the concept of SDM (13-15) and conditions for its success in hospitals (48) and literature on illness, care, and healing (49, 50).

3. Results

An overview of the number of the participants included in the activities appears in Table 1.

3.1. Lessons from the SDM training module

3.1.1. Evaluation meetings

At the evaluation meetings (two meetings with the trainers from the department of oncology and one meeting with trainers from four other departments at the hospital), the participants expressed some confusion regarding the concept of SDM, in particular struggling to understand how SDM differed from skills described in the CC-guide that focused on “involving the patients.” This gave rise to the question of what skills the participants needed if they had already learned SDM (without having called it SDM).

Different suggestions related to these questions were discussed at the meeting with the trainers from the four different departments. The trainers emphasised that the trainees’ main problem in implementing what they had learned was to be mentally present and listen without interrupting. Therefore, the trainers suggested a stronger integration of “involving the patients” and relationship skills from the CC-guide into the SDM curricula.

All three focus groups emphasised that preparation before the SDM course was very important for the outcome. Consequently, it was suggested that future participants be encouraged to bring decision-making cases from their own clinical practices and prepare videos that included decision-making activities.

However, as it could be difficult for nurses to identify decisions relevant in clinical nursing, it was suggested to create videos visualising the different situations where decisions occur (for example, decisions about nutrition, rehabilitation, and pain relief). Furthermore, different expectations on the role of the nurse in consultations where treatment decisions were on the agenda were also discussed, and as a consequence the decision was made to put more focus on how to facilitate a dialogue about roles and expectations in the decision-making process.

3.1.2. Questionnaires

A total of 44 (92%) participants responded to the questionnaire (Table 3). In general, they were highly satisfied with the course and indicated that they would recommend the course to their colleagues. The participants also indicated that the most beneficial aspects of the course were reviewing their own videos (n=30), role-playing (n=24), having discussions (n=15), and the number of participants (n=12). In contrast, the results suggested that catering (n=6) and support handling a camera (n=6) were lacking.

Based on the responses from the questionnaires, we decided to maintain the training module with the adjustment that had been made during the PAR process. The responses also supported the decision to focus on developing relevant practice-related videos.

3.2. Lessons from the theatre workshops

The theatre workshops shed light on the manifestation of the patients' many existential challenges when difficult decisions had to be taken. Moreover, the improvisational theatre work confirmed recent literature that SDM is not only about the relationship between the physician and the patient; this work showed that it can be a significant challenge to include both the patient and their relatives in the consultation process and to sufficiently address their responses.

Furthermore, it became clear that health professionals often struggled with addressing existential issues, which manifested the importance of recognising and reflecting on one's own limitations. More precisely, it illuminated how allowing yourself as a professional to be mentally present, to respond to cues and concerns, and to facilitate talks concerning existential issues such as the end of life, fears, hopes, and beliefs were of vital importance, however challenging.

In the consultations where both a physician and a nurse were present, the role of the nurse was vague. Nonetheless, it was revealed that nurses frequently play important roles in other contexts; for example, dealing with some themes that are not mentioned in the consultation with the doctor.

In the afternoon session with only the health professionals and the researchers present, the skills required to meet the challenges elucidated in the morning session were on the agenda. Subsequently, approaches to supervision were discussed and tried out on the stage, which made it visible that talking about personal barriers in communication and related feelings was another important challenge to address.

In order to give other health professionals similar possibilities of reflections on communication skills based on clinical cases, videos that can be used in communication courses or at reflection meetings for health professionals were requested. The videos were conceived to illustrate "real-life" decision-making, thus including scenarios with different kinds of "openings" for individuals to address existential distress (e.g., utterances of difficult feelings, unexpected behaviour, etc.).

3.3. Lessons from the reflection workshops

A total of three reflection workshops were conducted. Based on the input from the activities described above and the literature regarding SDM in health care, it became evident that the concept of SDM is fluid. From viewing SDM as a choice between two or more options that could be recognised as "preference sensitive," the broader definition of SDM was introduced and discussed. We experienced that the broader definition reflected the complexity demonstrated in the

theatre workshops and also necessitated by real-life scenarios where patients have multiple health problems and poorly defined treatment options (14, 15). We became aware that there are often multiple clinical decisions in effect (48) and very often patients do not have clear, stable, and strong preferences that they can simply declare (14).

Instead of approaching patients as people who govern themselves and know what they want, we discussed the consequences of approaching patients with the logic that Mol (49) refers to as “the logic of care” (as opposed to “the logic of choice”). By using the logic of care, one recognises that the experience of being a patient means feeling vulnerable and disempowered (13, 15, 49); this is an approach that focuses more on the well-being of the patients than the cure (50).

Additionally, we discussed if the relationships between patients and health professionals may facilitate processes that can release unused resources and lead to improved patient well-being (50-52).

We concluded that the one-day training course focusing more specifically on the SDM was insufficient to equip the health professionals with skills that could support the patients in their existential journey where significant clinical decisions have to be made. The findings called for supplementing traditional training with, for example, simulated patient exercises, self-reflection, and ethical reflections on what constitutes good care.

3.4. The concrete outcomes of the entire PAR process

The modified SDM module is now part of the communication programme at Lillebaelt Hospital. As a consequence of the PAR process, it will be supplemented with other modules aimed to equip health professionals with additional skills important for facilitating SDM. Communication modules regarding existential issues will be tested at the Department of Orthopaedics and the Department of Oncology in 2018. It will be conducted as a blended-learning intervention consisting of three three-hour modules combined with an e-learning platform containing reflection videos and exercises designed for rehearsal and reflection in-between the modules. The main purpose will be to raise awareness on the significance of existential and spiritual themes in connection with decision-making, including also the individual's own experiences with existential issues. Furthermore, focus will be placed on developing participants' self-awareness as well as their skills in responding to patients' existential concerns (53).

Additionally, a training module where the focus is on mindful awareness such as listening and on being present is under development as a one-day coaching course and was first tested in the Department of Urology in 2017. Mindful awareness has been found to stabilise

individuals' attention and helps them to avoid "acting automatically" so that they can act with compassion, technical competence, presence, and insight (54).

4. Discussion and conclusion

4.1. Discussion

Although we originally intended to develop and test an SDM training module, we changed direction and chose to engage the stakeholders in a deeper research process investigating required SDM skills. This was done in recognition of the circumstance that a crucial precondition for improving and changing practice is empowerment of those who are involved and on establishing powerful relations (55, 56). Furthermore, we recognised that we needed more knowledge about how decision-making was interpreted and handled in clinical practice and more knowledge about the experience of other researchers.

Historically, PAR has primarily been used in public health research and health promotion (38-40) and it is a well-proven methodology to generate knowledge, to educate both researchers and participants, and to achieve action-oriented outcomes (42). However, to our knowledge, there are no published research studies where PAR has been used to investigate, develop, and test communication skills curricula in health care. Therefore, in the absence of comparable studies, we focused our discussion on the impact of the PAR process according to the validity criteria, including the evaluation of the democratic validity, outcome validity, catalytic validity, process validity, and general validity (42).

In order to promote the democratic validity of PAR, we included relevant stakeholders such as patients, health professionals, and researchers (also from other research units) throughout the entire process (42, 57). The content of the course had been discussed with both external researchers in communication and communication trainers (clinicians), but patient input was only obtained in the theatre workshops. It can be regarded as a potential weakness in democratic validity, however, as some of the activities aimed to discuss scientific knowledge and the consequences of the PAR process on the development of curricula; we are unsure whether including patients in these activities would have yielded substantially different results.

Outcome validity is a test of the extent to which the actions occur (42), and good "action research" relies on "the quality of action which emerges from it, and the quality of data on which it is based" (58). Throughout this process, we used very different kinds of actions and methods to obtain distinct but complementary data on the same topic (59). We experienced that this

approach improved our understanding of SDM and the training that SDM skills require. The theatre workshops gave us the opportunity to “give life” to concrete dilemmas and challenges related to SDM and discuss them with both patients and clinicians. As in other studies, we found that despite the events “on stage” being fictitious (although based on actual clinical cases), the participants regarded these events as realistic (60) and effective to foster difficult conversations (41).

Catalytic validity is defined as “the degree to which the research process reorients, focuses, and energises participants toward knowing reality in order to transform it” (42, 61). In particular, we determined that the theatre and reflection workshops reinforced the catalytic process and contributed to the substantial change in our understanding of decision-making and the skills that it requires.

Nevertheless, the validity of the process is strengthened by our triangulation of methods and because our findings are a result of a series of reflective cycles that included ongoing problematisation of the practices by multiple stakeholders and patients (62).

The fact that the programme that we are now planning is in line with the tendencies reported in recent international literature (10, 13, 14, 16, 24, 63-65) also improves the general validity of the programme. Our research shares similarities with a study conducted by Körner et al. (66). As shown in our research, they found that respect, trust, and individualised treatment were important in SDM.

Our more broad communication programme may not only mirror the changes that the concept of SDM is undergoing, but also the change in the approach to patient-centred communication and patient-centred care. It aims to equip health professionals with skills that can make them responsive to and thus accepting of the patient’s needs, values, and preferences with respect to the content of encounters, the style of communication, and involvement in decision-making. Moreover, this dynamic is not focused on a specific set of behaviours, but requires skills that enable one to respond to multiple and often competing considerations given that it is rooted in the assumption of diversity in patient identities and a focus on the particularities of each encounter (14, 67, 68).

4.2. Conclusion

By involving patients, researchers, health professionals, and other stakeholders in a comprehensive process based on PAR, we were able to identify valuable skills that can help address communication challenges in SDM. Accordingly, we decided that future training in clinical

decision-making should pay more attention to SDM as a process that must foster patient autonomy, not only respect it.

We have drafted a communication programme in which role-playing, videos, and self-reflection exercises are used to facilitate a focus on clinicians' awareness of the feelings, values, and reactions of themselves and their patients. This programme aims to enhance skills toward the development of a practice characterised by mindful and responsive dialogues on the expectations, values, concerns, and hopes of patients and their relatives.

4.3. Practice implications

Using PAR as a methodology to identify the communication skills required turns out to have practical implications for the content of our communication programme, and unlike most SDM training courses, it is now based on a broader approach to SDM.

We suggest that before integrating new communication training concepts in organisations, PAR can be used to improve understanding the concepts and identifying the needs and priorities of both patients and health professionals.

Competing Interests

No competing interests.

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Figure 1 Illustration of the PAR process including the cycles of actions and reflections, the lessons learnt (LL) and the outcomes.

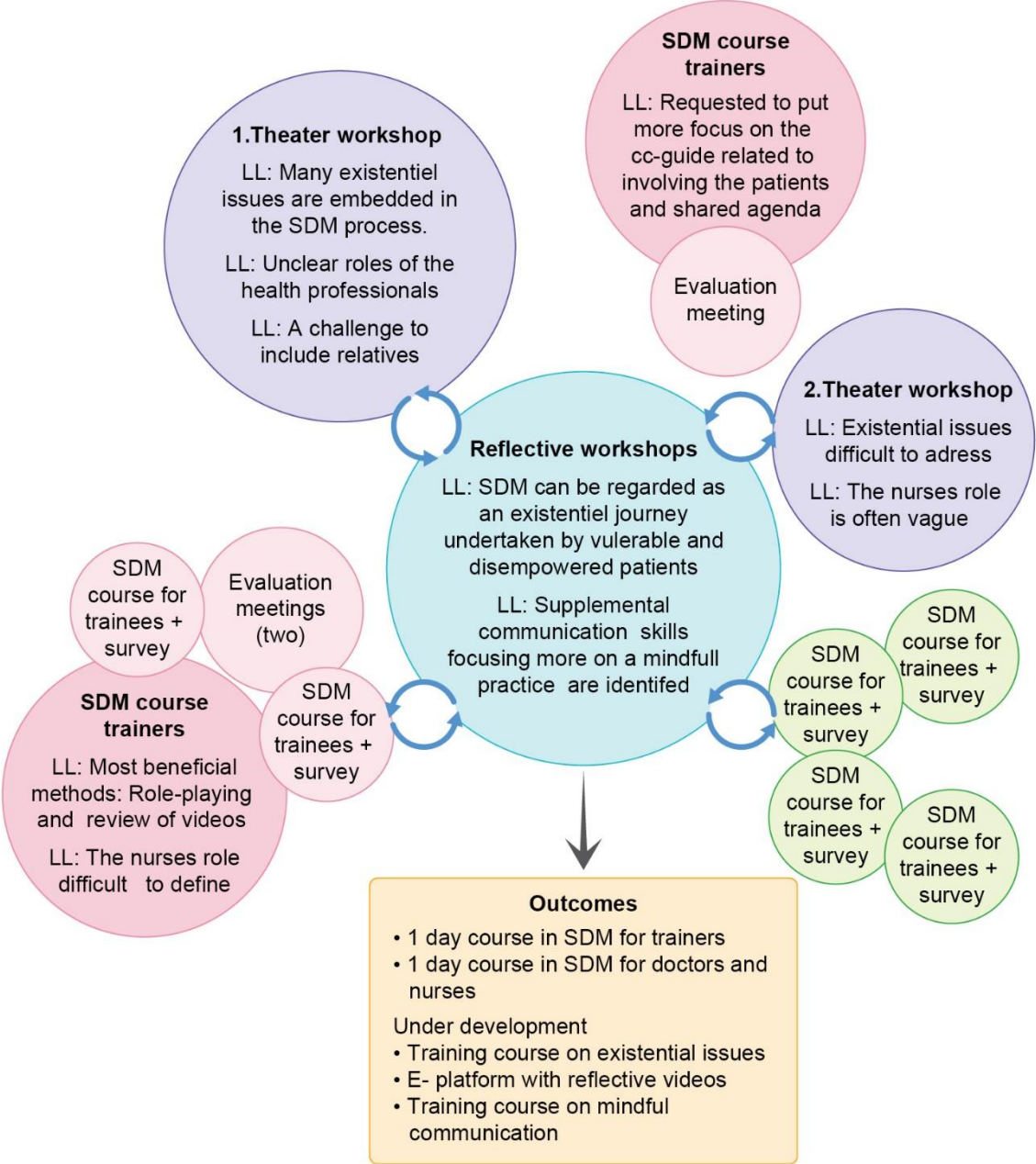


Figure 2 The process for testing and adjusting the SDM training course

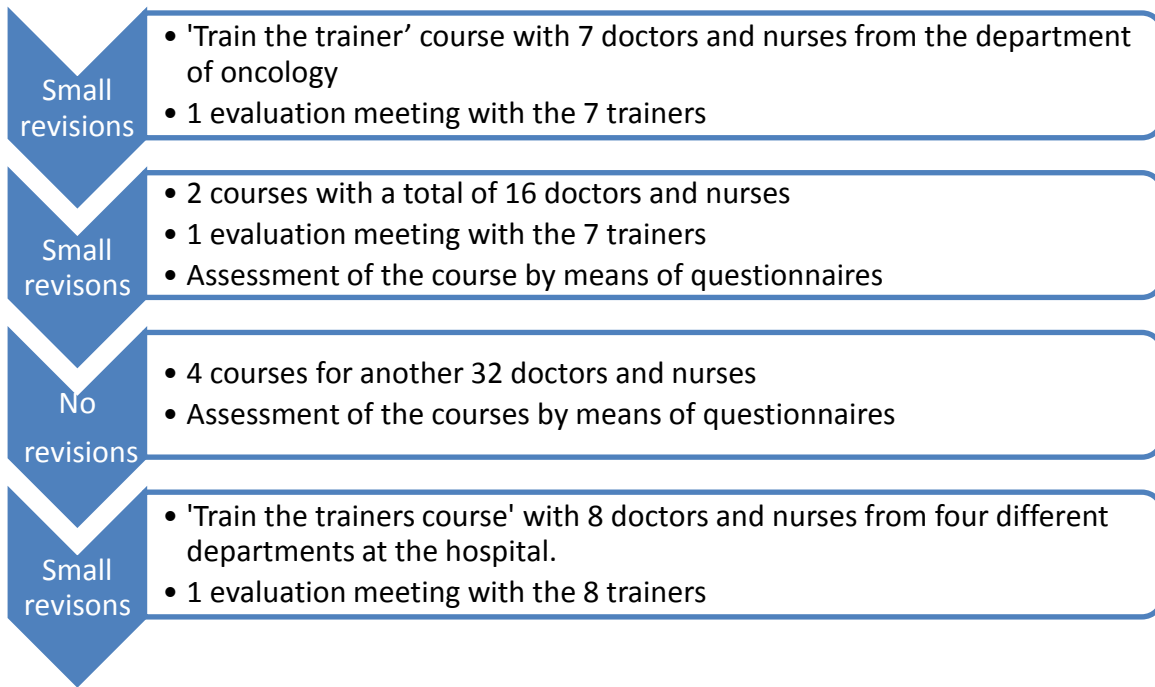


Table 1. An overview of the participants included in main activities used to provide knowledge and reflection in the PAR process

Activities	Participants	Approx. number of participants in each activities*
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

*Some of the participants participated in more than one activity

Table 2 The timing of the activities

Activities	2015	2016												2017		
	Dec	Jan	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar
SDM course for trainers																
SDM course for trainees																
Survey																
Evaluation meetings																
Theater workshops																
Reflection workshops																

Table 3. The trainees' responses to the one-day course in SDM, measuring their satisfaction and their learning outcomes (N=44).

To what extent do you think the course met the proposed aims?	Range ¹	mean (SD)	median (IQR)
<i>Experience connection of involvement skills with own clinical practice (N=44)</i>	6-10	8.16 (0.96)	8 (1)
<i>Develop a professional language about patient involvement in decision-making(N=44)</i>	6-10	8.09 (1.07)	8 (1.5)
<i>Try out elements of patient involvement/SDM skills (N=43)</i>	6-10	8.35 (0.92)	8 (1)
Satisfaction	Response ²	n (%)	
Overall satisfaction with the course (N=44)	1 (very high)	28 (63.6)	
	2 (high)	16 (36.4)	
Personal benefit from the course (N=44)	1 (very high)	23 (52.3)	
	2 (high)	21 (47.7)	
Satisfaction with the trainers' performance (N=43)	1 (very high)	36 (83.7)	
	2 (high)	7 (16.3)	

1) on a 1-10 scale, where 10 equals *very high*

2) on a 1-5 scale