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"A waste of time without patients": The views of patient representatives attending a workshop in evidence-based practice

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Abstract

Background: Shared decision-making is a central element of evidence-based practice (EBP). Training in EBP has traditionally focused on providers, but there is an increasing interest in developing such educational resources for patients. The aim of this study is to explore the views of patient representatives attending a workshop in EBP.

Methods: We conducted three focus groups with participants attending EBP workshops in 2013, 2014, and 2015. We used the framework method for content analysis. We reviewed the transcribed interviews independently and assigned initial codes and final categories to the transcriptions. We created an analytical framework and a flow diagram to visualize the category hierarchy and the relationship between categories.

Results: We identified two main themes; "How to facilitate training in evidence-based practice for patients," and "Outputs of training in evidence based practice for patients." Training in EBP for patient representatives "should reflect the principles EBP," and include interaction with both health professionals and other representatives. The educational needs of representatives are much the same as those of health professionals, and the training should therefore be "on a par with professionals." The relevance of such training may depend on the representatives' mandate, and costs might be an important barrier. Important outputs of such training include "becoming a knowledge manager," "enabling participation and informed decisions" and "re-defining the patient representatives' role."

Conclusions: The findings of this study suggest that training in EBP is attractive to patient representatives with outputs perceived important. Organizers should consider the principles of EBP when planning such training.

KEYWORDS

continuing education, evidence-based practice, patient education, user-involvement

1 | BACKGROUND

The role of the patient has changed dramatically the last century.[1] Moving away from a paternalistic decision-making model, patient-centered health care entails shared decision-making, mutual responsibilities, and transparency through shared information.[1] This change in culture has been driven by many factors, including such arguments that participation is a democratic right, and seen as important for quality assurance of health care by patients acting as "watch-dogs."[2,3]

Patient involvement and participation have been advocated for public health reasons,[4–6] and found to improve quality of life and health outcomes.[7,8] Many patients today participate on a system level, as activists involved in political processes, as board members in decisions about organization of health care or in prioritization of new treatments or technologies, in formal education of health professionals, and as researchers in biomedical research.[9–16]

Consequently, the patients' new role does not only come with new opportunities, but also with challenges as many of these new responsibilities require that patients have access to reliable health information. However, such information is not readably available, and many patients do not have the necessary skills to assess the reliability of health

information they are faced with through family and friends, in the media or even by health professionals.[17–23]

Training in evidence-based practice (EBP) has largely been focused on providers, however in the last years there has been an increasing interest in developing such educational resources for patients and the general public.[24–26] According to the Sicily Statement on EBP, "Evidence-Based Practice requires that decisions about health care are based on the best available, current, valid, and relevant evidence. These decisions should be made by those receiving care, informed by the tacit and explicit knowledge of those providing care, within the context of available resources."[27]

Every year the Norwegian Public Health Institute hosts a five-day workshop on EBP. The practical strategies taught at the workshop have been developed over the past three decades by clinicians, epidemiologists, biostatisticians, health economists and others. The workshop is designed as a small group, problem-based approach to learning where participants are divided into groups according to their area of interest and prior level of experience. Each small group is participant-directed and sets its own agenda, including which healthcare topics or questions to discuss.

During the week, all participants meet once a day for a plenary session, usually on a methodology topic relevant to all participants regardless of which small group they have signed up for. Upon completion of this workshop, participants should be familiar with EBP as a method and be able to formulate research questions that can be answered by the literature; identify core research designs and be familiarized with levels of summarized evidence (the s-pyramid); search for relevant evidence; critically appraise the validity and applicability of the evidence identified using relevant checklists; and make judgements about the certainty of the evidence using the GRADE approach

The workshop usually also includes plenary sessions and discussions about methods for implementing evidence into practice and patient involvement.

In previous years, participants have included physicians, nurses, policy makers, physical therapists, medical librarians, healthcare journalists, healthcare consumer advocates, and educators. Beginning in 2013, the workshop also welcomed patient representatives acknowledging the importance of patient involvement in health care.

In order to inform further development and planning of this workshop particularly tailored to the needs of patient representatives, we sought to explore the patient representatives' experiences as workshop participants. For this study, we used the framework method, which is a qualitative method for content analysis. This approach has typically been used in policy research, but is increasingly being used in health research.[28,29]

2 | METHODS

2.1 | Design

The Framework method is both descriptive and explanatory, focusing on relationships between themes and categories.[29] The method usually includes seven stages: (1) transcription, (2) familiarization with the data, (3) coding, (4) developing a working analytical framework, (5) applying the analytical framework, (6) charting the data into a framework matrix, and (7) interpretation of the data. It is important to note that this is an iterative process and that these stages may not take place in this order.

The method results in an "analytical framework," which refers to a set of codes and categories developed as part of the analysis to manage and organize the data.[28,29] Usually this is done by sorting an entering the data into a matrix following a tree diagram structure. In the charting and indexing, process codes are assigned to the data, themes are developed based on these codes with a number of categories entered into the analytical framework. A "theme" is an interpretative concept or proposition that describes an aspect of the data.[28] One or more categories are usually sorted under a theme. The term "category" refers to clusters of ideas or concepts that are related.[28] We describe each of the steps we took for collecting and analyzing the data below.

2.2 | Participants and setting

Twelve of the 29 patient representatives that attended the workshop between 2013 and 2015 participated in focus groups. All representatives were invited to take part at the end of each year's workshop. We held the first focus group, including four participants, at our institution in Oslo, six months after the 2013 workshop week. The following two focus groups in 2014 and 2015 included four and eight participants, respectively, and were held at the same location as the workshop immediately after the workshop week. The patient representatives that attended the workshops were all positive to the idea of participating in a focus group. For practical reasons, not all were able to attend. However, even though one meeting was held months after the workshop, and the two following meetings were held on a Friday afternoon after a long and intense workshop week, we were able to gather almost half of the participants.

The patient representatives filled more than one representative position. In addition to being members of various organisations within mental health, cancer, coronary health, musculoskeletal health, Myalgic Encephalomyelitis (ME/CFS), eating disorders and drug abuse, some also served as members on hospital boards, other advisory boards, guideline panels, or were involved in prioritisation of research projects and funding. Some were also involved in research projects, were responsible for providing members of their organisation with health information, had editorial responsibilities, served as counsellors or had an instructional role in their own organisation, for example, being responsible for assigning roles to other members. None of them had any prior training in EBP, although some had training in research methods as part of their professional education. The representatives had various professional backgrounds within teaching, information sciences, psychology, and economics.

2.3 | Data collection

Focus groups are suitable for producing a large amount of data in a short time and have been found to be a useful technique to shed light on topics that may be left underdeveloped in individual interviews.[30] Through group discussion, participants are able to make comparisons

between their experiences that provide access to information about both consensus and diversity of experiences.[30–32]

We conducted three focus groups with participants attending three different workshops in 2013, 2014, and 2015, respectively. One of the researchers led the interview. The other one took notes and supplemented the lead interviewer with prompts or additional questions when relevant.

The interview guide was semistructured and included the following topics: rationale for attending the workshop including prompts about understanding of own role as a patient representative, motivation for attending such a workshop, beliefs about EBP and the role of patient representative, and their experiences as workshop participants as patient representatives.

At the start of the interviews, the participants were informed about the purpose of the study, and the group agreed on a set of house rules. These rules included making sure that everyone was given the opportunity to speak. We also made it clear that the purpose of the focus group was not necessarily to achieve agreement, but rather to allow for discussion and to make room for different views and perspectives. Each focus group lasted about an hour and was audio recorded with permission from the participants.

2.4 | Data management and analysis

Analytic memo is a key term used within the framework method and refers to the process of memo writing as part of the analytical process to capture emerging issues.[28] This may inform restructuring of the interview guide and be used to inform the development of codes. This was performed by both authors during the interviews and when transcribing the interviews.

We transcribed the interviews verbatim. In the first phase of the analysis, we reviewed the transcribed interviews independently, and assigning initial codes to the transcriptions. After we had agreed upon the working analytical framework, we continued to code the remaining transcripts.[28] This process may include agreeing on the content and names of codes, as well as grouping and splitting of codes. The framework method can be used for both deductive and inductive research purposes or in a combination of these.[28] The final analytical framework is not established until all of the transcripts have been coded.[28] We agreed upon emergent themes and categories through discussions in an iterative process revisiting the data several times. Although we had decided a priori on a set of topics to be discussed and assigned to the interview guide, we were open for any new themes that possibly could arise during the interviews and analysis.

In concordance with the framework method, we created a matrix using Excel and entered all content from the coded transcribed text.[29] These codes were assigned to themes, categories, and subcategories.[29] These categories and subcategories were assigned to a flow diagram to visualize the hierarchy and the relationship between them.

We translated, from Norwegian to English, all quotes used in the findings of this paper. Doing so, we could not avoid rephrasing the quotes slightly. However, we believe we have achieved this without altering the content and meaning. The analytical framework includes quotes in both languages (Appendix 1).

3 | RESULTS

We present the main themes, categories and subcategories that emerged from our analysis. The complete overview is also available in a supplementary file (Appendix 1). Two main themes emerged: "How to facilitate training in evidence-based practice for patients" and "Perceived outputs of training in evidence based practice for patients." The findings below are organized accordingly (see Figure 1 for flowchart).

3.1 | Theme 1: how to facilitate training in evidence-based practice for patients

Two main categories emerged from this theme. First, a workshop in EBP "should reflect the principles of evidence-based practice, including both health professionals and patients." Second, there is no need to tailor an EBP workshop content to patient representatives in particular. Their training should be "on a par with health professionals" (see Figure 2 for flowchart).

Category 1.1. Should reflect evidence-based practice, including both professionals and patients

Including patients in the decision-making processes that are relevant to their health and their services is a requirement of EBP. Therefore, inviting patient representatives to attend a workshop in EBP seemed evident to the representatives. This, in their view, would reflect one of the fundamental ideas of EBP, informed and shared decision-making. As one representative said:

> "Without patient representatives, the workshop would be a waste of time."

At this workshop, patient representatives had the opportunity to meet, discuss, exchange experiences and learn about EBP in a protected environment, surrounded by peers. This was highly valued by the patients. In particular, the *"need for interaction with patients"* and discussing issues specifically relevant to their mandates was stressed as an important factor for future planning of workshops in EBP for patients.

> "I have absolutely seen how important it has been to have a group for patient representatives present."

However, several focus group participants wished there could have been more time allocated to interaction with other groups and group members. Although being part of an exclusive patient representative group had been rewarding, the representatives also expressed a *"need for interaction with professionals."* They felt that some of the small group sessions should have included a mix of participants from different groups. Each group could then be given a case to be solved within the mixed group with contribution from participants with different competences and from different backgrounds.

> "I think it would have been very useful and valuable if the patient representative group had worked together four of the five days of the workshop, and that we all worked interdisciplinary to solve a specific case in mixed groups for one of the days."
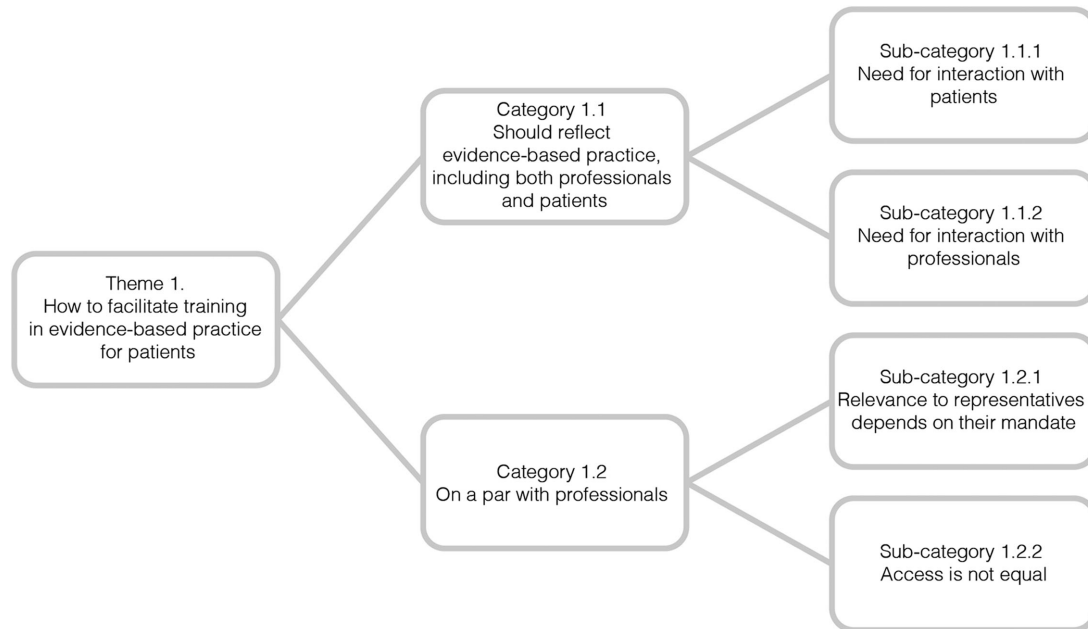
FIGURE 1 Flowchart—theme 1

Importantly, forming new multidisciplinary small groups would need to ensure a good mix of participants in order to avoid any possible power structure imbalances and to secure active participation from all the group members. This would require a more balanced number between attending patient representatives and professionals

Category 1.2. On a par with professionals

In regard to how the content should be tailored to their needs, they stated that there is no need to make any patient-specific adjustments. They considered themselves able to follow the same presentations and content as any other participant. A representative put it like this:

> "Our patients are well educated and our courses targeting our patient representatives need to match their level of education. Anything less will not be good enough."

The representatives discussed who would benefit the most from a workshop in EBP. Acknowledging that patients may serve very different purposes as representatives, they thought that the "relevance (of training in EBP) to representatives depends on their mandate." For example, training in EBP was considered more relevant for those involved in decision-making processes and for those responsible for disseminating health information to other patients. However, some representatives mostly work with peer support, and the patients considered that training in EBP would be less relevant to those.

> "We would be selective as to who we would send to attend such a workshop. It would be relevant for patient representatives serving as board members and involved in national guideline panels, those on a central level. In places like that, I think this knowledge is important. If it is peer support work, it is not so relevant. However, if your work involves more than that, this knowledge is impor-

tant to prevent representatives to give false alarm and to withstand pressure from the organization's members that sometimes voice strong opinions."

A central element to EBP is equity and shared information. However, a major barrier to equal access to training in EBP was costs. In Norway, patients are not paid for the work they do as representatives. Unlike most of the other participants that attended the workshop as part of their professional practice, the patient representatives had to take time off from any formal employed work, and had to cover the costs themselves unless they found someone willing to pay for them.

> "Cost is a challenge for many patient organizations."

Furthermore, it is not given that patients should receive such training, whereas this is a requirement of health professionals in Norway. A representative shared an anecdote about the guideline panel she contributed to, that had been sent to attend the workshop with their costs covered, with her as the patient representative, being the exception. This had strongly encouraged her to find her own means to be able to attend.

3.2 | Theme 2: outputs of training in evidence-based practice for patients

Three main categories emerged from this theme, with the perceived outputs being: 1: "becoming a knowledge manager," 2: "improved understanding of patient participation," and 3: "re-defining patient representative's role" (see Figure 2 for flowchart).

Category 2.1. Becoming a knowledge manager

One overarching goal for the representatives when signing up for the workshop was to be able to manage and navigate health information for use in their work.
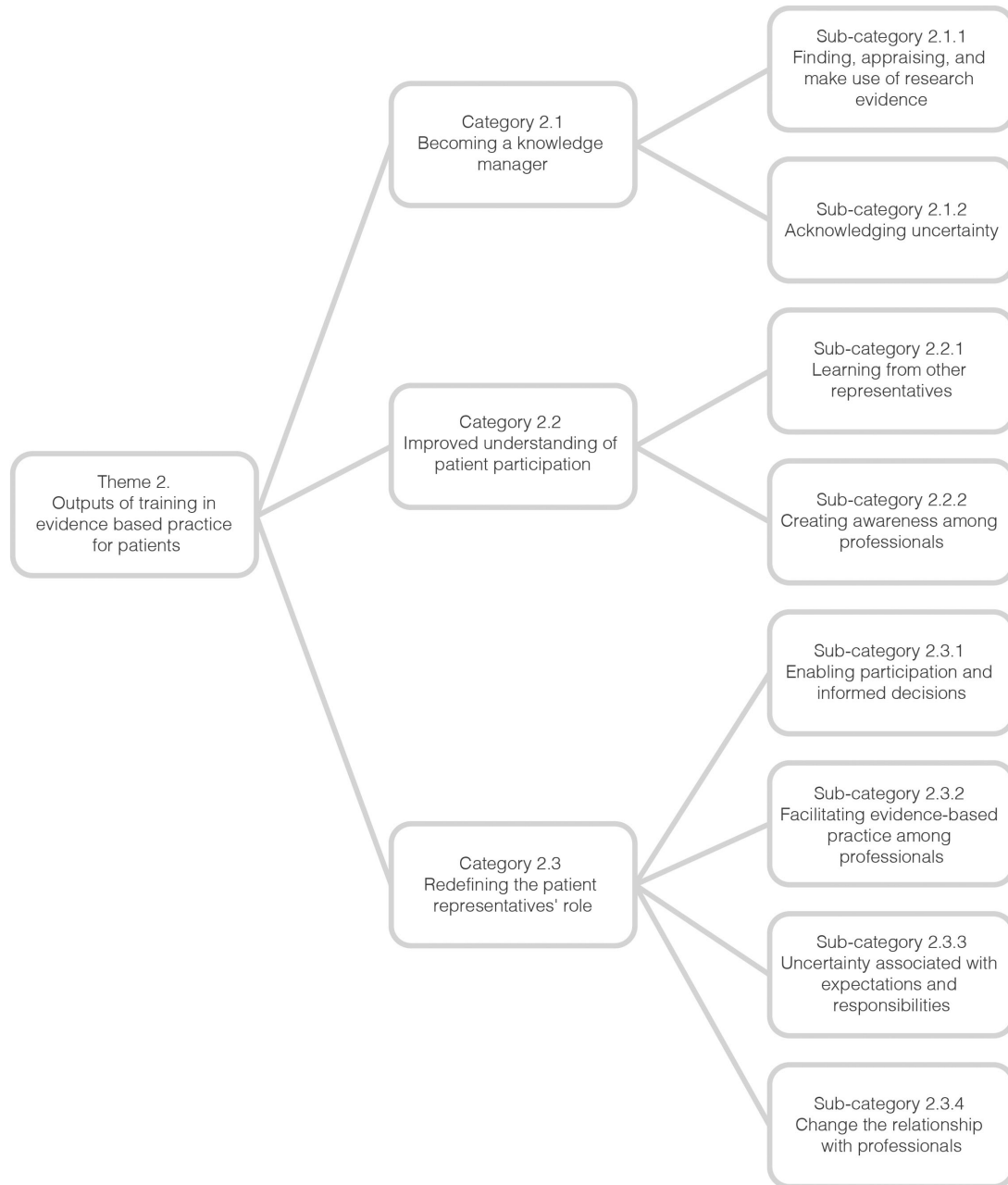
FIGURE 2 Flowchart—theme 2

"My motivation was to find research evidence, simply to learn how to best navigate in all what is out there. I think being able to do this will be two very important tools for me in the future. It has been really useful, and I am so grateful."

More specifically, they expressed the need for practical tools and skills that would enable them in *"finding, appraising, and make use of research evidence."* They also appreciated these skills that they had lacked, and that they previously may not have been so systematic in their use of health information.

"I think research is exciting and I read a lot of research papers in my work. But, perhaps I'm not always as critical as I should be. Sometimes I just choose the bits I like

to read. Being updated on using critical skills was very important."

Another major output we identified was that the representatives *"acknowledged the concept of uncertainty."* The workshop addressed uncertainty in two ways, either because of inconclusive evidence or due to lack of evidence. This was a topic that the representatives had often faced, and which had led to irritation and mistrust in evidence. For example, when media refers to studies with contradicting results, or when a specific treatment reported to be beneficial yesterday is found to be harmful today. Becoming aware of the reasons underlying such uncertainties was a revelation to the representatives.

"What I found the most important learning point was something I have felt for a long time—the

> uncertainty—the confidence in research that I have lost on the way, because there is constantly so many research results being published, and you know, do we really need it? However, what I have learned now, is that when you summarize all the available evidence, you can be more confident in the findings."

Discussions about uncertainties in research also played a part in nuancing the perhaps overly positive view on research evidence that some of the participants had, and to encourage a healthier skepticism.

Category 2.2. Improved understanding of patient participation

An important output from the workshop identified by the representatives was a greater understanding of the different roles and mandates patient representatives may have, and that user-involvement is a central element to EBP.

> "(I've) been strengthened in my view, that the user perspective should be included at all levels, whether it is in national guidelines work or in user committees. The user perspective should be included all the way, and not come in late in the process as part of a hearing or a formal meeting without any real meaning just so it can be signed off on a paper. It should be reel participation all the way."

This awareness resulted from *"learning from other representatives,"* but also that their presence at the workshop could *"create awareness among (attending) professionals."*

> "When I came to the workshop, I discovered that being a patient representative means many different things. I represent a very particular patient group, but now I have met representatives that have a much broader assignment than I have, and a very different definition from mine of what it means to be a patient representative. It has been good to be part of a group like this and to learn these things."

Although a lot of the work took place in individual small groups, the plenary sessions and social events included all participants. This became a venue for interaction and meant that patients, policy makers, and health professionals mingled on equal footing. They could for example participate in classes about statistics and developing evidence-based guidelines in the morning, and enjoy free time together in the evening. The representatives felt that having patients at such a workshop was of symbolic value and could create awareness and knowledge about patient involvement among the professionals.

> "I believe it is important that I am here, so that professionals get some input on what we are doing—how it works. Because, in many places there is little competency on patient participation."

Category 2.3. Re-defining the patient representatives' role

Participants believed that training in EBP could potentially re-define their role as patient representatives. One representative described her role as a representative in a research project like this:

> "I did not see it from the perspective of the researcher, but I do now. I think it makes sense to have a shared understanding of the language and terminology used, like we have been taught here. To know what it means. It will also strengthen my self-esteem being able to participate on equal terms, as a coinvestigator in a way. I think this is good to see."

They expressed that skills in EBP would empower them in their roles, and in *"enabling participation and informed decisions."* In particular, this would be useful when involved in allocating research funds, when identifying research gaps, and when developing guidelines. Such knowledge would also be important in their work targeting fellow members and political interest groups, helping them find information on which evidence-based interventions to pursue. Some participants had negative experience from being involved in tasks, which required research knowledge, and where their contribution, due to lack of such knowledge, had been limited.

> "When you as a patient representative are involved in a research project, you need insight into what it is all about. To be able to provide feedback, that is, to be a good participant in the process, you also need to understand the terminology used."

They also felt that being able to bring evidence to the table in discussions with professionals would give them more credibility and influence, as well as improved communication skills through a mutual shared language.

Some representatives saw as one of their responsibilities to be "watchdogs" for politicians as well as health professionals. Consequently, they considered improved knowledge about research to be a tool for *"facilitating evidence-based practice among professionals."*

> "I have met health workers that make their decisions based on ideology or previous experiences and not on research. But now I am able to ask: what evidence do you base this decision on?"

The representatives also acknowledged that training in EBP could result in *"uncertainty associated with expectations and responsibilities."* The kind of specialized knowledge this training gave could perhaps have the potential to differentiate them from other patients, and therefore disturb the "equality" within the community of representatives. They were also not sure which consequences, if any, this training would have on their future tasks and responsibilities as patient representatives.

> "I am unsure what my position and role will be from now on."

They also acknowledged that this knowledge would potentially *"change their relationship with professionals,"* but at the same time, they saw this as a necessary, although potentially challenging step on the way to achieve shared decision-making. For example, professionals may not all agree or consider it "natural" for patients to use and engage

in research evidence. Or they may be offended by patients who question the evidence underlying their recommendations or practice.

> "Health personnel and policy makers must learn to live with the new patient role. This is how the world progresses. I see no disadvantages in knowledgeable patients."

4 | DISCUSSION

4.1 | Summary of findings

As mentioned in the introduction, most educational initiatives in EBP and critical thinking has targeted health professionals, but there is an increasing interest in developing such initiatives for patients and the public.[24,26,33–35] Based on the findings from this study, such training should reflect the principles of EBP and include both health professionals and patients. The patient representatives we interviewed valued the time spent in the patient-only group, discussing issues that were specific to their mandates as representatives. However, they also saw the benefit of more interaction across participants' groups. For example, it was suggested that group work including patients, health professionals, and policy makers would have provided valuable experience and resembled informed decision-making in practice.

We found that training in EBP can be delivered in much the same way as for health professionals. Although the examples and terminology used in training of patients and providers may vary, the educational needs seem to be similar.[36–40] Organizers of EBP workshops also need to keep in mind that patient representatives may in fact *be* health professionals or have a background in science. We also found that the relevance of training in EBP is dependent on the representatives' mandate. Whereas some representatives engage in work that requires such knowledge and skills (eg, in guideline development or providing other patients with health information), others mostly spend their time providing peer-support.

Cost was a factor that prevented equal access to training in EBP. Whereas many health professionals get the costs covered by their employer, many patient representatives are volunteers or not formally employed and have no budget to cover costs for continuing education. Adding to this problem, the patient representatives perceived that funders of this kind of training might consider such skills irrelevant to patient representatives.

We identified three main outputs of training in EBP. A major output was to become a "knowledge manager" by being able to find, appraise, and make use of research evidence in their work. The large amount of information, and not knowing what to trust was something they all were struggling with as representatives. They were also familiarized with the concept of scientific uncertainty, which made a big impression on them.[41,42] All of a sudden, they understood the reasons behind scientific uncertainties, and they now had tools to address this issue.

Interestingly, an important output of the workshop was improved understanding of the many roles and mandates patient representatives may have and also that patient-involvement is central to EBP. This came

as a result of discussing with peers, but also through interaction with other participants at the workshop. Training patient representatives in EBP might be something new and uncommon to them, but perhaps a workshop including both patients and professionals, that follow the same curricula, might be equally new and uncommon to many professionals.

Another important output of training in EBP was that being able to find, assess, and apply research evidence could re-define their role as representatives. First it would enable them to participate in decisions more effectively and enable them to make evidence informed decisions. Traditionally, patients' (expected) contribution in decision-making has been to provide their own experiences, preferences, and values.[1] However, representatives increasingly engage in activities that require them to understand and apply research evidence. Without such skills, representatives may feel powerless and unable to participate effectively. In a study by Dickersin et al. on science training for breast cancer activists, the participants felt more confident, asking more critical questions and were more actively engaged in finding health information.[24] Similarly, a feasibility study of training of patient and consumer representatives in evidence-based medicine by Berger et al. found that the participants felt empowered and more confident.[26]

Training in EBP was also identified in our study as a means to influence health professionals, by engaging the representatives to ask for evidence and to enable them to assess the reliability of recommendations. This is an important finding in line with evidence on patient involvement that may improve health care and patient safety through patient demand for evidence-based health care.[8–10]

However, training in EBP was also found to result in some uncertainty and other potential challenges. By becoming knowledge managers, the representatives felt that this would potentially differentiate them from their peers. They were also uncertain whether this, from now on, would require them to take on other tasks and responsibilities. The interviews also discussed potential negative reactions from health professionals to train patients in EBP. In other studies, training in EBP has been found to lead patients to acknowledge their right to be informed,[26] but also to challenge the relationship with health professionals by "rocking the power balance."[43] Furthermore, EBP is still not uniformly accepted among providers. Consequently knowledgeable patients may experience that they are more updated on the latest evidence than their providers, which may result in conflict and confusion.[43] Despite this, the representatives we interviewed expressed that patient participation is a necessary step on the way to an evidence-based health care.

4.2 | Limitations and strengths

This was a small study, and the views of other patient representatives' might have been different. There is no gold standard for deciding the point of saturation.[44] Our sampling and data collection was pragmatic.[44] Although including participants from later years may potentially have contributed to, or changed our conclusions, the views of the participants from the three workshops we included were coherent. Another potential limitation to this study is that not all participants

were able to attend for practical reasons; however, there is no indication that the views of those who attended the interviews deviated from those who were not able to attend.

For this study, we used the framework method. This method has several benefits. These includes the possibility of handling large amounts of data, the systematic procedure, and most importantly the clear audit trail leading from the raw data to the final framework.[28,29] Although the method has been criticized for its "quantitative" and reductionist aspects, it relies on an iterative process including familiarization with the data, continuous discussions and refining of codes.[28,29] To improve credibility important for rigor, both researchers took part in the describing of the data. We also reviewed and coded the transcripts independently before deciding on the final themes and subcategories. We also believe that our multidisciplinary background was useful in this process providing us with different perspectives in the data collection process and analysis. In addition to being a teacher in EBP, AA has a social science background including training in knowledge translation and science studies. MJ is an information specialist with training in philosophy. Central to the framework method is the production of an analytical framework where all relevant content from the transcribed text is entered.[29] This process provides transparency to this study and is a systematic approach to data collection and synthesis.

We have made effort to provide insight into the methods we have used and provided access to the data material and associated findings to improve rigor. However, we acknowledge that other researchers may have come to conclude differently. A potential danger in all qualitative research is that the method involves some level of subjectivity. Therefore, findings from qualitative research should at every step of the research process be considered in light of potential influence from the researchers.[31] Reflexivity is central to the analysis and subsequent interpretation of findings. The weeklong workshop in EBP is an intensive course, with discussions going on from early morning to late evening. As the patient representatives' tutors, we shared their journey throughout this week. Although this may potentially have influenced the participants' reporting (eg, causing acquiescence bias or social desirability bias), we also believe that our role in the workshop was beneficial for this study. First of all, we were involved in all group discussions during the workshop, and to a certain extent, came to know the representatives. They also came to know us and consequently felt free to share their beliefs and attitudes as part of the focus groups. The familiarization with the participants also gave us a thicker background when analyzing the findings from the interviews. Furthermore, the purpose of this study was not to evaluate the participants' satisfaction with the workshop. That was done by others at the end of the workshop and by using quantitatively methods for nonresearch purposes.

Based on the findings from this study, training in EBP for patient representatives should reflect the principles of EBP and include both health professionals and patients. In terms of how the workshop was organized, the patient representatives valued the possibility to engage with other representatives, but also saw the benefits of interaction with other participant groups with health professionals and policy makers. Our study also suggests that when it comes to training in EBP, the needs of patient representatives are much the same as those of health professionals. The relevance of such training may depend on the representatives' mandate, and for patient representatives, costs might be an important barrier to attend. Important outputs of the training included the opportunity to become a knowledge manager, an improved understanding of patient participation, and a re-definition of the patient representatives' role.

Ethics (and consent to participate)

Informed consent was received for all participants. We received ethical approval by the Regional Committees for medical and health research ethics in Norway.

COMPETING INTERESTS

AVAILABILITY OF DATA AND MATERIALS

All results are published as part of this study.

ACKNOWLEDGMENT

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