

## **Alignments and differentiations – people with illness experiences seeking legitimate positions as health service developers and producers**

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### **Abstract**

Health policies and strategies promote the involvement of people with illness experiences on service development and production, integrating them into settings that have traditionally been domains of health professionals. In this study, we focus on the perspectives of people with personal illness experiences and explore how they justify involvement, position themselves as legitimate actors and forge collaborative relationships with health professionals. We have used discourse analysis in analysing individual interviews conducted with peer support workers and experts by experience (n=17) who currently work in Finnish health services. The interviewees utilised discourses of empowerment, efficiency, and patient-centeredness, aligning themselves with the justifications constructed by patient movements additionally to those found in current health policies. Both groups wanted to retain critical distance from professionals in order to voice criticisms of current care practices, yet they also frequently aligned themselves with professionals in order to gain legitimacy for their involvement. They adopted professional traits that moved them further from being lay participants sharing personal experiences and adopted an expert position. Although national level policies provided backing and legitimacy for involvement, the lack of local level guidance could hinder the practical implementation and make involvement largely dependent of professionals' discretion.

**Key words:** expert by experience; Finland; health services; patient involvement; peer support worker; qualitative

### **Introduction**

The involvement of people in health care decision-making has become a guiding principle of public health service reforms in a number of western countries (Coulter & Magee, 2003; Martin, 2008). Involvement has been described as a way to foster services that are more responsive by including the 'patient perspective' (Rowland et al., 2017). Hence, both members of the public and people with personal illness experiences are now increasingly included in *service development; evaluation of services; education and training* of health professionals; and *co-production* of services (Tritter, 2009). In some countries, they are also able to take part in *health policy planning* and *research activities* (Dent & Pahor, 2015). Consequently, lay people are now able to participate in decision-making on a service level and deliver services jointly with professionals. In this study, we will explore patient and public involvement from the perspective of people with personal illness experiences who are actively participating in service development and production. Involvement can be seen as an empowering process that provides a voice for illness experiences and helps make health services more patient-oriented. However, integrating people with illness experiences into health services as developers and

co-producers is a pursuit that raises conflicts and tensions. It also requires motivation and tactical skills from lay participants who need to justify their involvement to different stakeholders, negotiate entry into service settings and then attempt to establish a position as legitimate actors.

Involvement can be justified in a number of ways that consequently influence its practical implementation. Newman and Kuhlmann (2006) have argued that on a policy level, involvement is often interpreted as a cost cutting activity that transfers more responsibility onto the people utilising services. The rise of chronic illnesses and aging populations has led to governments implementing reforms that are committed to cost effectiveness, accountability, competition and consumer choice (Starr & Immergut, 1987). Hence, people with lived experiences that engage with health services are expected contribute to the enhancement of service quality and cost reduction. From the perspective of health services, involvement fits with the ethos of patient centred care and joint decision making that have been integrated into clinical practice. Involvement can be justified by arguing that it leads to patient empowerment. However, there are issues that often remain unaddressed such as unequal power relationships between patients and practitioners (Barnes & Cotterell, 2012). Involvement and the cultivation of individual choice and agency can provide professionals with valuable capital, yet involvement does not automatically translate into new or empowering forms of practice (Leppo & Perälä, 2009).

Additionally, a great number of patient organisations and user groups in the form of critical self-help groups and social movements, such as the women's health movement or gay rights activism in relation to HIV/AIDS (Barbot, 2006; Dent & Pahor, 2015) have created a pressure to democratize health related decision making. These movements have addressed issues ranging from provision of services and health inequities and challenged science on etiologic, diagnosis, treatment and prevention for a number of decades (Brown et al., 2004). Although involvement in health service development and production is a relatively new development, these movements have paved the way for patients to be seen as experts in relation to their own bodies and health conditions. The apparent rise of consumerism has also led individual service users rejecting or being encouraged to reject a passive trust in medical expertise and medical reputations; expressed in among other things through more involvement in decision-making (Elston & Gabe, 2013).

On a more practical level, prior studies have highlighted the lack of clarity and the tensions associated with people with illness experiences entering health services. Some of the tensions arise from the attempts to establish experiential knowledge as a valid form of expertise in a setting where (bio)medical knowledge and research based information are considered to form the basis of reliable and legitimate expertise (Caron-Flinterman et al., 2005; Greenhalgh et al., 2015). Collins and Evans (2007) have described an increasingly dis-embedded world where who is considered an authority or an 'expert' and what types of knowledge are regarded as credible and trustworthy, are contested. People with personal illness experiences can be seen as part of this challenge as they claim to have experience based knowledge and expertise, which needs to be incorporated

into healthcare. However, despite the increase in involvement opportunities, people with illness experiences lack a clear position within health services where the medical model continues prevail.

Secondly, the people who participate in health service development and production are faced with unclear and at times conflicting expectations. Martin and Finn (2011) have suggested that service users who are included as team members can be particularly vulnerable to role blurring as they lack the identity and skills base that defines a profession. Gates and Akabas (2007) have argued that professionals can experience role confusion and have difficulties relating to workers with personal experiences if they are not sufficiently prepared for their arrival or are unclear what their work should entail. This lack of clarity can lead to mutual powerlessness experienced by health professionals and people with personal experiences as they struggle to find ways in which this new group of workers could contribute in health service settings (Broer et al., 2012). People with illness experiences can become integrated into healthcare teams, where they can demonstrate personal recovery and enhanced the team's skill-mix (Gillard et al., 2013). However, as they adopt a more professional position the 'giving of personal experience' can become less appropriate or viewed as unprofessional (Gillard et al., 2013). Thirdly, the overall aims relating to involvement can vastly differ between stakeholders. For example, Rutter et al. (2004) have argued that people with illness experiences who participate in development work want to make concrete changes and improvements, whereas service management may expect them to conform to set agendas.

As demonstrated above, entering health service settings as newcomers and with a considerably different knowledge base is not a straightforward task. We wish to contribute to the growing literature on patient and public involvement within health services by focusing on the perspectives of people with illness experiences who are attempting to engage with professionals, and become integrated into health services. Our first aim is to explore the ways in which they justify their involvement as different justifications can offer an insight into ways in which people interpret the aims and underlying values related to involvement. Justifications can also be utilised in a tactically to provide a legitimate base for involvement. Our second aim is to study how this new group of participants attempts to establish a legitimate position for themselves within health service settings that are historically hierarchical and operate from a different knowledge base.

The data used in this article has been collected in Finland, which is a relative newcomer when it comes to involving people on service level developmental work and service production. Although the Act on the Status and Rights of Patients (785/1992), strengthening people's right to be involved in decision making on individual care, was passed as early as the 1990s it was not until the 2000s that involvement in a service level rose on to the policy agenda. During the 2000s the mental health and substance abuse strategy begun to actively promote involvement (Ministry of Social Affairs and Health, 2009). Following the parliamentary elections in the spring of 2015, the newly appointed centre-right coalition government continued to include involvement into their Strategic Programme (2015) for health and welfare. During this period, several developments took place. Firstly, experts by experience were increasingly involved in managerial groups, training of health professionals

and service delivery. The position of experts by experience within mental health and substance abuse services has been further cemented as the Ministry of Social Affairs and Health (2018) published a statement that their involvement is to become a legal requirement. Secondly, training of experts by experience widened in scope as several regional health service authorities began to offer training to patients and coordinate involvement activities. Peer support work is also being increasingly recognised as a valuable asset and support workers are moving more into hospital settings, where they can be in closer contact with patients and health professionals. Several hospital districts have founded patient information centres where trained volunteers can provide support and information to patients. Additionally, there has been an increase in patient forums that are used in the assessment and development of care services. Ollila and Koivusalo (2009) have argued that concurrently with these developments, business and economic interests were taking a guiding role in health and social policy choices. Indeed, Finnish health policies tend to frame involvement as a measure through which services can become more cost-effective, customer orientated and of enhanced quality (Anonymised, 2017).

We have chosen to focus on two participants groups: experts by experience, working in mental health services, and peer support workers, working in cancer services, which are offered most direct service level involvement opportunities. Peer support worker is a term commonly used in cancer services and cancer patient organisations. Peer support workers undergo a short training course that qualifies them to provide peer support to others. Cancer peer support workers have a long tradition of providing support through third sector cancer and patient organisations. These organisations operate independently from health services and peer support workers have not been present within health service settings. Over the past few years, there has been a slow change particularly within larger cities and support workers have entered hospital settings. Examples of this include giving talks at events organised by hospitals for newly diagnosed cancer patients and their family members. Some larger hospitals also have patient information points, where patients can meet peer support workers. The term expert by experience is not yet widely used among people with lived experiences of cancer. However, some cancer organisations have also begun to utilise the term and train people to become experts by experience. Experts by experience either work in community services as paid team members or hold a seat in management/development groups within community and hospital settings. The term expert by experience has become widely used within mental health services and among people with lived experiences of mental health problems.

What also strongly connects our interviewees is their emphasis on lived experiences. They have embodied experiences, which can not be read about or taught. Embodied experiences are at the core of experiential knowledge and as Brown et al. (2004) have argued, the experiences lend moral credibility both in the public sphere and the scientific world. Additionally, all our interviewees had been involved in development work and/or provided services to patients. As prior studies indicate, involving people with personal experiences is becoming a more common practice in a number of countries (e.g. Shuval et al., 2002; Gates & Akabas, 2007; Martin & Finn, 2011; Broer et al., 2012). In order to make involvement meaningful to these groups of

participants and to health services, it is important to study their position, contributions and experiences of collaboration in more depth. The aims of this article are to explore 1) what justifications do people with illness experiences provide for their involvement and 2) what kind of strategies do they adopt in order to establish a position within healthcare services?

## **Methods**

### *Interview materials*

We have analysed in-depth interviews conducted with experts by experience and peer support workers (n=17) that currently participate in the development and production activities within mental health and cancer services in Finland. By involvement in service development, we refer to participation in any work that includes service planning (participation in managerial/planning/development groups). By service production, we refer to work, which takes place in health service settings such as hospitals and health centres where people with illness experiences provide support and advisory services to patients. The participants were aged 23-71 and all of them had personal experiences of mental health problems or prostate cancer. The first author recruited interviewees by contacting patient organisations, which provide training and act as the main points of contact for health services for recruitment. Prior to the interviews ethical approval was sought from the relevant ethics committee. All the participants gave verbal and written informed consent. The first author conducted the interviews during autumn 2016 and spring 2017. A topic guide covering different themes (such as motivation, experiences of working in different settings, training and content of different work tasks) acted as a basis for each interview, but it was used loosely to allow participants to freely discuss their experiences and introduce issues, which they regarded as important.

### *Analysis*

In our analysis of the interview materials, we have taken a discourse analytic approach that views language as a means to construct social understandings of the issue in question (Potter & Hepburn, 2008). Our focus has been on the ways in which peer support workers and experts by experience justify their involvement and how they position themselves within health service settings. We have studied the patterned ways of thinking that can be identified in the verbal communication of our interviewees. Their ways of talking are also connected to the sociocultural and political context in which they occur (Lupton, 1992). As discussed earlier, service user involvement and the integration of people with illness experiences into health services is a new phenomenon in Finland. Our interviewees have been using services as patients but as collaborators and joint decision makers, they are newcomers. Following the initial stage of familiarising ourselves with the interview materials and discussing tentative findings, more specific research questions were formulated: Firstly, what justifications do peer support workers and experts by experience provide for their involvement? Secondly, what kind of strategies do they use in order to establish themselves within health services? These questions were used to direct in-depth reading of the data.

At this phase, we focused particularly on parts of the interviews where participants discussed their work in health services, described their entry into service settings. Davies and Harré (1990) have defined positioning as ‘the discursive process whereby selves are located in conversations as observably and subjectively coherent participants in jointly produced storylines’. Positioning is closely connected to the way in which one compares and evaluates self with other as ‘we become and are ourselves only in relation to others’ (Shotter, 1993). By looking at the ways in which interviewees described themselves in relation to professionals and patients, we could explore the strategies they adopted to establish themselves as similar yet distinctly different from both of these groups. These differentiations also made it possible for them to argue for increased involvement and present themselves as vital and important actors in health service planning and production. Whilst analysing the interview materials, we noticed that although peer support workers and experts by experience talked about issues in very similar ways, there were also differences. Although this is not a comparative study as such, in the results section we have at times contrasted between these two groups. At the final stage of the analysis, we grouped data extracts under core ways in which peer support workers and experts by experience justified their involvement, described their entry into and positions within health service settings.

In the next section, we will discuss the ways in which peer support workers and experts by experience attempt to negotiate access to healthcare settings and establish a position for themselves. The part is divided into three parts, first of which explores the ways in which interviewees justified the need for their involvement. The second part focuses on their attempts to gain access into healthcare environments and the ways they attempt to produce themselves as legitimate actors. The third part focuses on the issues that can hinder involvement and position peer support workers and experts by experience as outsiders, even when they appear to be working in collaboration with health professionals.

## **Results**

### *Empowerment, efficiency and patients’ needs – justifying involvement*

The interviewees provided a variety of justifications for their involvement, some of which were deeply personal whilst others utilised similar justifications to those provided by health policies and patient organisations. On a personal level, involvement entailed rehabilitative aspects. Being involved signified a new stage in recovery and interviewees could argue that their involvement sent out a sign that people with illness experiences could provide important perspectives and challenge preconceptions associated with different illnesses. Indeed, all the interviewees argued that involvement was a way to challenge presumptions, address shame and provide others with hope.

Expert by experience: *What I consider as the most important duty is removing the shame from the mental illnesses and then the other one is giving hope.*

Some of the justifications stemmed from personal experiences. Participants described the feelings of confusion associated with navigating the care system and making treatment decisions. They felt that it was important to ensure that current patients had the opportunity to receive more guidance, talk to someone with the same

experience and be provided with information about different options available. One of the main arguments for the inclusion related to enhanced communication with patients. The interviewees argued that health services were overstretched in terms of resources. The inclusion of people with illness experiences could ease the pressure on professionals and allow patients much needed time to talk.

Peer support worker: *It [the health care system] is stretched so tightly (...) They [people working in health care] are being rushed and then you have to prioritise your work. Possibly this kind of volunteer could have more time to spend. And that's just what a person needs when they've gotten ill.*

Peer support workers described themselves as peers, who had a strong embodied understanding of what it is like to live with cancer. They knew about different care pathways, managing side effects of treatments, and how difficult it could be to talk about the illness. As the interviewees had all experienced prostate cancer, they also talked about the potential shame and embarrassment that some men experience as prostate cancer treatments can lead to urinary incontinence and sexual dysfunction. Professionals were depicted as authoritative figures, whose knowledge was often limited to clinical issues. In contrast, peer support workers described themselves as *'equals'*, *'more practical'* and *'down to earth'*. Similar argumentation was also used by experts by experience who worked in close contact with patients. The assumption was that people would have less trouble opening up to them.

Peer support worker: *...doctors will tell you if you ask them, but as I said, these are incredibly difficult things for most men to be asking about from others. However, one to one with a peer, who is after all a stranger to them, but has been through the same, it can be easier to open up.*

All the interviewees referred to health professionals' knowledge base as limited in some ways. Health professionals lacked the lived illness experience and even if they had personal experiences, they were often unable to share them within the boundaries of professional practice. Experiential knowledge was described as a new resource, which could benefit professionals and patients. It also differentiated experts by experience and peers support workers from health professionals into a distinctly different group that in the words of the interviewee below, have their "own expertise".

Expert by experience: *I was just talking to a psychiatrist and they had run out of ideas with a patient. They could adjust medication and such but they didn't really have the tools for anything else. So they were thinking that I could meet the patient. (...) And I feel that my encounters [with professionals] have been such that I have my own expertise and they have the expertise of their own field.*

The justifications provided above stem from the distinct nature of experience and discourses of empowerment and inclusion. However, within health services, experiential knowledge is often at a disvalued position and hence justifications stemming from experience alone were insufficient. Hence, interviewees utilised health policy rhetoric such as patient centeredness and cost effectiveness. In the extract, the interviewee lists a number

of benefits for involving people with illness experiences, suggesting that it can bring benefits both on personal, service and national levels.

*Expert by experience: Well, it's cost efficient and then it's a rehabilitative activity. (...) And they've emphasised, probably because of the health and social care reform, customer orientation. What could be more customer orientated than experiential expertise.*

Overall, the interviewees discussed how meaningful involvement had been in terms of their personal recovery and how it provided them with opportunities to challenge shame and stigma. Nevertheless, the justifications that stemmed from the ideas of empowerment were not sufficient. Here justifications and the need for legitimacy overlap, as the interviewees utilised policy rhetoric in order to both justify involvement and to construct themselves as legitimate actors. They produced an image of health professionals as clinical and distant, lacking lived experiences of coping with an illness. Health services were described as overburdened and un-capable of responding to the varied needs of patients. Involvement and the inclusion of experiential perspectives were described as the way to provide a truly patient centred and efficient service, which could take into account clinical aspects and psychosocial support needs. By utilising multiple and varied justifications, the participants were also able to form a more solid argument for their involvement. Additionally, partial alignment with health policy aims could also support them as they were attempting to negotiate access in health services.

#### *Legitimacy and access to health service settings*

As prior studies have shown, practical implementation of involvement is often a challenging process and different stakeholders can hold conflicting views on the aims of involvement. In our study, the interview participants acknowledged that involvement in Finland was a new development and in many ways, they were the forerunners who could pave the way for others. This also meant that they needed to negotiate with health professionals in order to gain access into new service areas and present themselves as legitimate actors whose views should be taken into consideration. In order to do so, the interviewees used varied strategies that both aligned them with and differentiated them from health professionals and patients. Peer support workers were still at a beginning phase when it came to entering health service settings. They work actively within the voluntary sector; however, their entry into health services is currently limited to hospitals. In hospitals they face further confounds, as the physical spaces in which they operate are limited to communal areas. Patient information centres operate within hospital lobbies and information events for new patients are held in auditoriums and other public areas. Entering a hospital in the first place was described as a demanding task. Access to healthcare settings was not automatically granted. It needed to be negotiated and often required backing from more authoritative figures. In the extract below, the peer support worker describes using backing from the head of the organisation.

*Peer support worker: At the [local hospital] there is this patient information centre. (...) It's like a booth at the end of the hospital. (...) and my idea is that I'm gonna push my way in there with*



*a help form the [head of the patient organisation]. (...) I also know that when a man comes from there and he has lots of questions that he didn't think of asking and the doctors are busy. They are experts in their field but they don't have time to comfort or explain. (...) But definitely they should provide something and I'm trying. I've got a mission that I could infiltrate that place and the people would know who I am and what I'm doing.*

Those who had managed to enter into hospitals were slowly trying to widen the physical space that they were able to access as support workers. One interviewee describes his attempts to gain access into the part of the hospital where patients receive prostate cancer diagnoses.

*Peer support worker: I've really tried to get in there, from the cancer clinic to the urology clinic where the diagnosis place is. That I could get to the start of the path. But there are certain barriers clearly and those need to be broken one way or another, with persistence if nothing else.*

In contrast to peer support workers, the interviewees who worked as experts by experience had been able to gain access into a variety of health service settings. They held seats in service level planning groups in hospital and municipal services and worked as paid members of community care teams. Whereas peer support workers were attempting to find a way past the hospital lobby, experts by experience had managed to open these doors. This also meant that their work duties were more varied and most of the work was not done with patients, but also in collaboration with health professionals. Nevertheless, “*breaking down doors*” was also a feature in the expert by experience interviews as they were attempting to both secure their positions and to create new work for themselves and others.

*Interviewer: Would you tell me a little bit about the different forms of work you've been involved in so far?*

*Expert by experience: Well, for example I've been in this research project where they test, it's a joint study between the [university] and [hospital district]. There are three rounds and I'm in the middle one and I run a support group for eight weeks as an expert by experience at a psychiatric polyclinic. And then there's a comparison group who just fill in forms about how they feel and a professional run activation group. I hope that this study could show the benefits and how much group treatments can help and how much experts by experience or using this kind of service can benefit patients. And I hope it will increase job positions for example at the psychiatric polyclinic. I've got large-scale plans in mind. (laughs)*

The interviewees wanted to be seen as legitimate actors, able to comment on services, provide advice and work jointly with health professionals. However, they did not have professional qualifications, the content of their work lacked clear definition and many of them were voluntary sector actors, not paid employees. They attempted to differentiate themselves from other service users as well as health professionals by emphasising their training, knowledge and skills. Experts by experience had undergone training that lasted for several

months and they expressed strongly that training should be a prerequisite for the work that they did. Peer support workers' training only lasted for a few days, but all the interviewees agreed that it needed to be compulsory. Past training and work experience were also described as sources of knowledge and skills that could be applied in the healthcare contexts.

*Expert by experience: And now I'm undertaking this training in substance abuse work and that's an important step. You can build yourself up and maybe it gives you more credibility in these working groups and projects.*

Additionally, interviewees attempted to create wide networks to gain influence and during the interviews, they drew attention to their connectedness by namedropping well-known doctors or describing involvement in high-level service management groups. These activities aligned the interviewees closely with professionals and involvement opportunities appeared to be dependent on personal networking abilities. However, active involvement also required the interviewees to constantly learn more and train themselves further. Many of them used professional terminology, were familiar with the latest treatments, talked about new medications and their availability and explained what the care pathways for different patients were. Although they emphasised their knowledge of the everyday life, they were also required to adapt to institutional settings by understanding the professional lingo.

*Expert by experience: I always google the terms at the table when I'm listening to organisational level stuff, so that I don't lose face by asking hey what are you all talking about.*

The interviewees talked about their experiential knowledge base, which was a combination of personal illness experiences, experiences of other patients, knowledge of the care system and information that had been gathered both from scientific and non-scientific sources. Despite utilising personal experiences, they emphasised the importance of distance and the ability to adjust to different service settings where new specialist knowledge and skills needed to be obtained.

#### *(Un)equal collaborators – working with health professionals*

In health service settings, the interviewees came into close contact with professionals. Some of them worked side by side, whilst others worked in the same physical area but not necessarily in collaboration. Both peer support workers and experts by experience discussed their interactions with health professionals in positive terms and many had felt that their views were valued. Nevertheless, there were also barriers to joint working. These could include physical barriers such as limited workspace within hospitals or barriers related to their position within the professional hierarchy. In the extract below, the interviewee describes how he is invited to speak at information events aimed at newly diagnosed patients. However, his talk is always scheduled last, after talks from all the health professionals.

*Peer support worker: I've been to these information events that they have at the hospital every two months. I've signed up for those and I gladly go there to visit. At the end of the day when everyone is alert and has been listening to those lectures all day then I'm the last one who talks*

*there. I look at my watch to see how much time I have before it's 4 o'clock. Then I do a small thing about peer support groups, although there aren't many people there then.*

Although, experts by experience had gained entry into a wider variety of health service settings, their place within these services continued to be vague and a source of confusion among professionals.

*Expert by experience: It's been a few years since I signed a contract with them. And some of the nurses I've known since I started going to there, but there are also new people. And at first, they didn't really know how to take me, like is she a patient or a client or a care worker or an agency worker. So first, it was like that. Then they accepted me and sometimes I even get praise. But then it's things like, I cannot give out medication and such. So even if they are grateful then I still feel that they are professionals and I'm just a peer or an agency worker or. No, no, I don't think they consciously do it.*

Practical implementation of involvement was still very much reliant on professionals' attitudes. One of the interviewees, who was working in a service development group alongside professionals, talked about some of the other members choosing not to communicate with him.

*Interviewer: You've worked in a lot of places. What has the reception been like from the different professional groups?*

*Expert by experience: It's been varied. I've been lucky that a couple of years ago I got into the psychosis services management group. (...) I've been lucky to meet a few people who are positive about experts by experience and understand the meaning of experiential knowledge. You notice that the reception has been varied and you notice that with some people there just hasn't been any communication. And when you meet them it can be just like hi, nice to meet you. But then there are those who are in touch on a weekly basis and want to know what's going on.*

These examples do not show an outward rejection of peer support workers or experts by experience. However, these subtle things can reflect certain ambivalence towards involvement. Although service strategies present involvement as a necessity, there is very little concrete guidance on implementation, which can lead to confusion and uncertainty. Our interviewees were eager to engage with health services, but their views could also differ in relation to the level of integration they wanted to achieve. Some were striving to become paid employees whereas others were only willing to engage as voluntary actors who may lack a legitimate position but are able to maintain a critical distance to services. The country context can also be a factor, as in contrast to countries such as Canada, the UK, or the US, peer support workers in Finland do not receive pay for their work. All the interviewees had completed training to become peer support workers, spent a considerable amount of time engaging in support work, attended lectures and followed new research developments. Yet, some of them saw themselves as volunteers and even suggested that receiving a wage could compromise their credibility.

Peer support worker: *But this cannot become a job, because once you start doing it as a job, you're just doing it for the pay and it loses its meaning.*

In the above extract, the interviewee also makes a difference between support workers and professionals who do receive pay. Support work is described almost as a calling and doing it voluntarily highlights their commitment to helping patients. However, this is not a view shared by all the peer support workers and some were hoping that they could become a more established part of health services. Experts by experience currently have many more paid work opportunities available to them and hence a legitimate position within health services can appear much more achievable. However, these arguments over pay highlighted the conflicting feelings our interviewees held in relation to integration. Some of the interviewees were afraid of losing their connection with patients or not being able to voice criticism if they became paid employees. Others argued that the lack of pay placed them in a differential and potentially less valued position and in the extract below, the interviewee questions whether it is fair that people whose resources are limited due to the illness as expected to work free.

Expert by experience: *I gladly do things on a voluntary basis, but when you think that you're a rehabilitee and only have a limited amount of resources that you're using on something. Then in a way, you're doing a lot of stuff free when you're not able to do actual work. And maybe your work would be more highly appreciated if you were paid for it.*

Another aspect that could influence peoples' views on pay was their position in the job market. Some of our interviewees were retired and were not actively looking for a second career, whereas others had lost their previous jobs due to the illness and for them gaining paid employment could be seen as an important goal or a benchmark.

## **Discussion**

Integrating people with personal illness experiences into health services has become commonplace in a number of countries and involvement is high on the health policy agenda. Hence, in this study we have focused on involvement from the perspective of lay participants and explored the justifications they provide for involvement, how they attempt to negotiate access into varied health settings and establish themselves as legitimate actors and collaborators. Based on our results, we would describe involvement as a balancing act as people with illness experiences are expected to represent the voice of experience and align themselves closely with other patients. However, attempting to become legitimate actors in health service settings place new requirements on them and can lead participants to adopt more professionalised traits. Our interviewees appear to move fluidly between service settings, stakeholder groups and different roles. In order to find their own distinct position they need to both align with and differentiate themselves from patients, patient organisations, health professionals and health policies.

The interviewees also displayed a high level of discursive competency, as they were both aware of the different justifications provided by patient groups and policy makers and able to utilise them effectively. They aligned

themselves with the empowerment discourses of patient movements that place emphasis on recovery and hope (Hui & Stickley, 2007). However, they also utilised rhetoric that was borrowed from Finnish health policies and strategies (Anonymised, 2017). They acknowledged that policy documents provided backing for their inclusion and due to this, the language of empowerment was often mixed together with patient-centeredness, quality and efficiency. They also provided concrete examples, arguing that patient centred care required people with illness experiences to be included in service planning and development. Additionally, they claimed that having someone with personal experiences working in care settings offered patients opportunities to share their feelings and experiences more openly. One of the central justifications for involvement contained criticism of health professionals' abilities to respond to patients' needs and challenged health professionals to take into consideration the emotional and social aspects of illness. Hence, the interviewees aligned themselves with the longstanding criticism that biomedicine in particular fails to locate the body within its socio-environmental context (Nettleton, 2006). Some were even involved in ongoing research studies in order to gain evidence that involvement in service production could produce direct benefits to patients. By doing so, they were able to tactically produce a more solid foundation from which they could argue for involvement and attempt to establish themselves as legitimate participants within health services.

Although involvement receives a lot of support from policies and strategies, at least on a rhetorical level, it does not automatically secure entry into community and hospital settings. Gaining physical access to hospital settings proved to be rather challenging and peer support workers in particular were often confined to communal areas such as lobbies. Access to hospital wards required further negotiation, which highlights the position of experiential workers and experiential knowledge in relation to the position of health professionals and their knowledge base. Shuval et al. (2002) have argued that hospital medicine in particular represents the 'ideological, epistemological, and institutional core of biomedicine' (2002: 1745). Hence, without thoughtful planning and facilitation it can be difficult for people with illness experiences to become integrated into an institutional setting with its existing customs, norms and cultures. The strategies utilised by our participants included networking and collaborating with professionals who were keen to promote involvement. Through these networks, they could gain access into new areas and gain new work opportunities, which in turn helped them become more established and recognised among professionals. However, based on our findings, health services' commitment towards involvement appears rather ambivalent. Involvement is promoted, but its success is not actively facilitated by anyone. One consequence is the feeling of not fully being part of the team or being confused about one's position within a service that bears similarities to 'mutual powerlessness' described by Broer et al. (2012). These feelings can stem from lack of guidance and planning, which can lead to confusion over job duties and responsibilities. Poorly defined job roles can also hinder integration into the work place and can make it difficult for participants to be successful in their work (Jacobson et al., 2012). Although joint working with professionals was described in positive terms, involvement was often reliant on the professionals' discretion. In order to be seen as a legitimate participant, the interviewees were expected to adjust and learn the institutional lingo and practices.

People with illness experiences are required to create close relationships with health professionals in order to gain access into services. As mentioned before, participants can also be expected to adapt their behaviour. In our findings, we can see elements of professionalization of lay participants (El Enany et al., 2013) as many of the interviewees frequently used professional terminology, actively sought the latest information on service developments and treatment options and differentiated themselves from other patients. Integration into health services can limit the amount of criticism that participants can voice and potentially depoliticise involvement. Indeed, prior studies have suggested that involvement in health care raises a risk of services colonising experience based work (Rebeiro Gruhl et al., 2016) and limiting the sharing of personal experiences (Gillard et al., 2013). In order to be seen as legitimate actors, our participants differentiated themselves from other patients by imposing their own requirements for involvement. Maguire and Britten (2017) have talked about the lack of specialist knowledge and education being central requirements for involvement, as participants are expected to provide lay perspectives on issues. Although, our participants emphasised the importance of experience training had become an unwritten requirement amongst both groups, allowing them to enhance their skills, process their experiences and produce a story that they could use as a tool in different working environments. They also highlighted other qualifications, communication, IT and media management skills, which were deemed as necessary. The strong emphasis on training may be due to the country context, as Finland has a strong cultural tradition of valuing education. However, these ‘qualifications’ also produced boundaries and access requirements that can lead to others being excluded from involvement activities.

Despite aligning themselves with other professional groups, the participants also wanted to ensure that they could maintain a sense of independence and freedom to express critical opinions. They wanted to ensure that they did not lose their authenticity as people with embodied illness experiences. Our participants expressed their determination to discuss their personal experiences openly, describing it as a central part of their work and crucially important in their attempt to challenge stigma and provide hope. In the future, it would be important to consider the steps that can be taken to ensure that participants are able to maintain their distinctiveness that stems from having personal experiences.

Although our study has highlighted the similarities experiences by peer support workers and experts by experience as they attempt to work within health services, we acknowledge that there are differences between these groups that do not relate to their work or job title. Our study participants have all experienced prostate cancer or mental health problems (depression, bipolar disorder, schizophrenia and psychosis). Mental illnesses continue to carry stigma and negative preconceptions that continue to be associated with these illnesses can have a strong impact on people’s lives and social relationships. These illnesses can be cyclical in nature, which means that the person never feels fully recovered although they may not experience any symptoms. Illness experiences vary greatly between individuals. However, prostate cancer usually occurs much later in life and although it is associated with shame and embarrassment, it is unlikely to impact on the person’s social life or

work prospects in the same manner as mental illnesses. Varied personal illness experiences, how specific illnesses are treated or perceived in society are also likely to motivate people to participate in different ways.

## **Conclusion**

This study has focused on the justifications they provide for their involvement that include the need to be cost-effective, increase patient orientation and provide holistic care to all patients. They also challenged health services by highlighting lack resources and the limitations of health professionals' knowledge base. Common experiences shared with other patients enabled them to argue that health services were unable to respond to emotional or social needs of patients or help them to navigate the complex care system. There were differences between the two groups, as peer support workers described difficulties in entering service settings and were more likely to work alongside professionals than in collaboration with them. Despite integration into service settings, the participants were still facing challenges due to the vagueness of their position and did not feel fully integrated even when they were paid team members. Overall, the position of people with illness experiences appeared to be a fluid as it could change and vary depending on service setting and the interpretations of the work content. Fluidity is also a reflective term to describe the positions peer support workers and experts by experience adopt in relation to professionals and patients. It was a balancing act to be seen as legitimate actors as it required aligning and differentiate themselves from these other groups, finding a space somewhere in the middle. On a practical level, it is important for services to develop guidelines and clearer job descriptions jointly with people with illness experiences and patient organisations. This can alleviate role confusion and 'powerlessness', which can be experienced by experiential workers and health professionals. Local level guidance is also required to reduce people with illness experiences having to rely on professional discretion to become involved.

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