

## **Personal perspectives on patient and public involvement – stories about becoming and being an expert by experience**

### **Abstract**

Patient and public involvement activities bring ‘lay participants’ and their accounts of lived experiences to the centre of health service development and delivery. For individuals, these accounts can provide an important resource, offering a sense of control and an opportunity to re-frame past events. Furthermore, as involvement activities and the use of personal accounts has become more prominent, it is timely to examine the involvement process from the perspective of the ‘lay participants’. Hence, the aim of this study is to explore how people become involved and how they construct the accounts of their lived experience. We analyse the stories of people with lived mental illness or caring experiences, who have become experts by experience (n=13). We argue that becoming an expert by experience can help to re-contextualise past experiences and support *the re-discovery* of skills and expertise, leading experts by experience to construct both *professionalised* and *politicised* identities. The process has the potential to enforce narratives that portray illness experiences as motivators for social action and change. Additionally, we claim that the stories experts by experience share with health services and the public are not ‘lay accounts’ or ad hoc tales, but accounts constructed to serve specific purposes.

**Key words:** identity, mental illness, narratives, patient and public involvement, professionalisation, personal stories, recovery

## **Introduction**

Bury (1982) has famously described illness as a biographically disruptive event that can force people to re-evaluate their life, values and behaviour. One way to make sense of a disruptive event and to regain control is for people to become storytellers and “recover the voices that illness and its treatment often takes away” (Frank 1995: xii). On a personal level, stories have the potential to support recovery and self-empowerment. However, stories can also have wider significance. The ‘narrative turn’ in society has shifted attention onto reflexive, subjective and culturally engaged first person stories (Grant et al. 2015).

Concurrently, the growing prominence of patient and public involvement initiatives, taking place in a number of countries (Dent & Pahor 2015), places personal experiences to the centre of service development. Personal stories about living with an illness or caring for an ill family member can be used to inform practice, health policy and the research agenda (Nielsen et al. 2013). Involvement opportunities have enabled a group titled experts by experience (Meriluoto 2017; Noorani 2013) or lived experience workers (Byrne et al. 2016) to participate in health service development and delivery. Experts by experience have lived illness or caring experiences that form the basis of the expertise and, which are utilised through different involvement initiatives. They can work as trainers, co-planners and co-producers alongside health professionals. There has been extensive research on patient and public involvement focusing on issues such as the conceptualisations of involvement, benefits of involvement for health services, problems related to implementation, and attitudes of different stakeholder groups (eg. Dent & Pahor 2015; Lehoux et al. 2012; Sholz et al. 2017). In this study, we will take a personal perspective on the involvement process and focus on the narrations of becoming and being an expert by experience. These personal stories also enable us to explore the opportunities and tensions associated with becoming involved, and how the process can influence the accounts experts by experience share with health services.

A central aspect of becoming an expert by experience is constructing a personal story, which can be used as a resource in involvement activities (Jones 2018). Prior studies have argued that becoming an expert by experience can be an empowering process that transforms the person from a patient into an expert of their

own condition and acts as a stepping stone back to “regular life” (Rissanen 2015:123). Toikko (2016) has suggested that becoming an expert by experience consists of individual and collective processes that include sharing experiences and creating distance from them, combining experiences with existing competencies and developing an orientation towards the future. However, as Meriluoto (2017) has highlighted, this process may also curb the participants’ freedom by creating standards and expectations on their narrations and making alternative ways of knowing appear ‘irrational’. Additionally, experts by experience are expected to be in charge of their experiences and associated emotions. Näslund et al (2019) have suggested that experts by experience need to learn to express their experiences in a way that produces “affective intensity, while not spilling over into uncontrolled illness” (Näslund et al. 2019:10).

In this study, we suggest that becoming an expert by experience can act as a springboard into a new life stage, where the illness experience is seen as a source of knowledge, expertise and a motivator for social action. However, the process of becoming requires individuals to share and produce a structured account of their lived experiences. Additionally, we argue that the process of becoming and the expectations placed on being an expert by experience can potentially marginalise certain narrative types, whilst enforcing the idea that illness experiences should act as sources of motivation and an opportunity for self-discovery and personal development. Before introducing our analysis and results, we will discuss the importance of personal stories for people trying to overcome a disruptive life event, which for our participants has been the experience of a mental illness or caring for an ill family member. Following this, we will briefly outline the policy and legislative context that guides involvement within Finnish mental health services and provide more information about the training process that prepares people to become experts by experience.

### **Personal stories, identity construction and cultural narratives**

Serious illness can have a number of long-term consequences for individuals and their family members, leading to personal and lifestyle changes (Reynolds 2003) including loss of employment, reduction in social networks, intrusion of medical treatments to daily lives and the need to interact with an array of services.

Additionally, mental illnesses can carry strong social connotations and conditions tend to vary in their severity, disruption and stigmatisation. Through personal stories, people can give meaning to their experiences, regain a sense of control (Kelly 1994) and re-establish legitimacy outside of illness (Charmaz 2000). Personal stories can also act as tools for identity construction (Bamberg 2011; Grant et al. 2015). However, the identities produced through narration can change over time and vary according to the situation. Hence, as Meretoja (2018) has suggested, they are temporal, situational and shaped by social and interactional contexts.

Although personal stories are based on individual experiences, they are not produced in a socio-cultural vacuum. Frank (1995) has suggested that while stories are individual, people compose them by adapting and combining culturally available narrative types. Some of these narratives can be described as culturally dominant (Kirkpatrick 2008). The dominant narratives regarding people with mental illness continue to relate to poverty, homelessness, or being involved in the criminal system, which can sustain discrimination and stigma (Kirkpatrick 2008). Existing side by side with these narratives are the historically dominant biomedical ways of understanding illness experiences. Although people with personal experiences have not constructed these narratives, they have the potential to be the paradigm through which we understand illness experiences and a standard against which people with personal experiences compare themselves (Bell 2014). In this study, we use the term narrative, when referring to larger collections of individual stories that follow similar form and structure.

The stories told by experts by experience, combined with the growing body of research conducted by people with personal illness experiences, have the potential to challenge biomedical and psychiatric narratives on mental health and distress (Landry 2017), as well as the identities imposed by dominant cultural narratives. Frank (1995) has focused on the personal stories told by people with an illness experience and described three 'narrative types' that people may adopt as they attempt to make sense of their experiences. The *restitution narrative*, often seen as medicalised, begins with health, followed by

illness and looks for a return to health in the future. The *restitution narrative* stands in stark contrast to *the chaos narrative*, which lacks a specific sequence of timing and “reveals vulnerability, futility and impotence” (Frank 1995:97). Lastly, *the quest narrative* portrays the illness as useful and has three subtypes: 1) memoir in which events are related simply; 2) manifesto in which illness becomes a motivator for social action or change; and 3) automythology in which illness is universally expanded to reveal faith or destiny (Frank 1995). Frank’s narrative types offer one way to understand the form of personal experiences. However, these narrative types are focused on the illness experience and subsequent recovery period. Nunes and Simmie (2002) have suggested that people have begun to move beyond the recovery paradigm to incorporate the experience into a larger life story. More recently, both Kirkpatrick and Byrne (2009) and Martin et al. (2014) have written about the narrative of ‘*moving on*’ that allows the individual to conceptualise the illness or other life event ‘as one of the many disruptions that can occur in daily life’.

We will focus on the stories told by people who have either personally experienced mental illness or cared for an ill family member, and who have subsequently trained as experts by experience. We will explore how they describe the process of becoming and being an expert by experience and how they construct their identities within these stories. Their stories relate to patient and public involvement, which has grown into a multifaceted phenomenon, implemented in numerous and heterogeneous ways (Bherer & Breux 2012). These developments have allowed ‘lay participants’ to engage with health services in a new way. Hence, our participants are members of a small but increasingly growing group of people, who are able to contribute to service development and delivery. The emphasis of this study is to explore stories of becoming and being an expert by experience that focus on life after a disruptive event. However, we cannot completely dismiss the stories about their illness and caring experiences. After all, the illness and caring accounts are processed during training (Toikko 2016) and the experiential knowledge derived from these accounts forms the knowledge base of experts by experience. Through involvement activities, experts by experience are using their experience-based knowledge to influence services. Hence, in addition to analysing the stories about becoming and being an expert by experience, we will also discuss how this

process can have consequences on ways in which lived experiences are verbalised and presented. Before introducing the materials and methods used in this study, we will provide a brief description of the training of experts by experience and introduce the policy and legal framework that guides their involvement.

### **Experts by experience in the Finnish context**

Patients' rights to participate in decision-making regarding their treatment were strengthened through legislation in the early 1990s. However, service level involvement (i.e. involvement in development and delivery) only became a prominent feature of health policies during the 2000s and 2010s (Jones & Pietilä 2017). The government, elected in 2015, continued to promote involvement in their Strategic Programme (2015) for health and welfare. Currently, health service organisations are not legally bound to involve patients, but many of them have adopted policies that support involvement. A statement published by the Ministry of Social Affairs and Health (2018) suggests that the inclusion of expert by experience in mental health and substance abuse services could become a legal requirement in the near future.

The use of the term expert by experience can be traced back to the 1990s, when a mental health organisation began to train people with lived experiences. Nevertheless, the term did not become widely adopted until 2009, when it was included in the National Programme for Mental Health and Substance Abuse (Ministry of Social Affairs and Health 2009). Since then, several voluntary sector organisations and hospital districts have begun to train experts by experience. Additionally, in 2012, a group of trained experts by experience founded their own organisation, which now provides training, manages work bookings, and participates in public discussions regarding involvement. The training is not compulsory and one can adopt the title of expert by experience even without the training. Nevertheless, the training courses are popular and provide a clearer pathway to those who wish to become actively involved. Training can also be seen to provide experts by experience with additional legitimacy to work within health services, alongside established professional groups (Jones & Pietilä 2018).

Due to the large number of training providers and the lack of mutually agreed content or standards, there are variations between training programmes. For example, the lengths can vary between two and nine months, with the participants attending training sessions approximately once a week. The training sessions are group based and commonly include information about working as an expert by experience, knowledge of the service system and legislation, information about mental illnesses (provided from the professional perspective) and practical support such as media management, marketing and presentation skills (Hirschovits-Gerz et al. 2019; Toikko 2016). Another core element of all training is disclosing personal experiences with the other group members, gaining feedback from them and constructing a personal story, which is rehearsed during the training. Although each individual participant develops their story from personal experiences, Meriluoto (2017) has highlighted that the training process can contain practices, such as the requirement to reframe experiences as neutral or objective, which restrict the participants' freedom to reconstruct themselves.

## **Materials and methods**

The individual interviews (n=13) analysed for this study were collected in Finland between winter 2017 and summer 2018 by the first author. Eleven of the participants had personal experiences of living with a mental illness (e.g. bipolar disorder, schizophrenia, psychosis, depression), one of them had experienced mental illness and cared for family members, and one had been a carer for their spouse. The participants were aged between 23-62. Four participants held professional health care qualifications, and had worked in health or social services prior to their illness. A vast majority of the participants had not been able to continue in their previous profession following the illness. All of them identified themselves as experts by experience. However, two of the participants had not taken part in formal training. Instead, they took part in a group where personal stories were shared and constructed in a similar manner to 'formalised' training sessions. The participants had been involved in the assessment and development of services and care pathways, training of health professionals or worked as co-producers, i.e. they were providing care services to patients jointly with health professionals. The first author recruited participants by contacting

organisations, which provide expert by experience training and act as the main points of contact 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 interviews were recorded and transcribed verbatim. In order to ensure anonymity, the participants have been given pseudonyms, which are used in the results section.

### *Analysis*

The initial idea of this article was sparked by our interest in 'lay participation' in Finnish health service development and delivery. More specifically, we wanted to focus on a growing group of people, who title themselves experts by experience, and explore how they construct their expertise and use their lived experiences. With these ideas in mind, the first author conducted interviews with people, who identified themselves as experts by experience. A topic guide covering different themes (such as motivation, experiences of working as an expert by experience in different settings, training and content of different work tasks) acted as a basis for each interview. However, it was used flexibly to allow for free discussion of topics the participants considered relevant or important. At the beginning of each interview, the participant was asked the question: Could you tell me how you became an expert by experience? Instead of providing a technical account of their training, the participants began to talk about their lives prior to becoming ill, their treatment experiences, the recovery process and subsequent training as expert by experience. Their experiences and work as experts by experience were further explored by asking questions that facilitate the telling of stories (e.g. could you tell me about the work you have done as an expert by experience; would you tell me about the challenges/rewards related to being an expert by experience). The interview materials were not initially gathered with a narrative analysis in mind. However, whilst reading through the materials, we noticed that the interviewees often talked at length about their experiences, providing examples, telling anecdotes and outlining how they 'transformed' from patients or carers into experts over a period of time. We found this process particularly interesting and wanted to explore it in more depth.

Hence, we decided to approach the interview materials as stories about the experiences and accounts of being an expert by experience after reading through the transcribed texts.

Our aim was to explore the ways in which these of active 'lay participants' are constructing their lives and identities following a disruptive event. Hence, we focused specifically on the types of stories told and the ways in which the participants positioned themselves within these stories, and also during the interview situations (Bamberg 1997, 2004; De Fina 2013). The questions we set out were: 1) *How do people with lived experiences describe the process of becoming and being an expert by experience;* 2) *What kinds of identities do they construct for themselves through their stories;* and 3) *What kinds of narratives do their stories draw from?* In the analysis, we approached the stories told during interviews as verbal acts that are performed in situated and interactional contexts (Bamberg 2011). The analysis was informed by Bamberg's (2004) suggestion that stories have different temporal levels and positioning can occur within the story as well as during the interactional situation where the story is being told. Additionally, Bamberg (2004) argues that people also position themselves in relation to the question "who am I?" and through this they take part in the construction of normative discourses.

The analysis began by first identifying stories describing the thematic content of becoming an expert by experience and working as an expert by experience. These accounts followed very similar patterns as the interviewees usually talked about their past illness or caring experience, their decision to attend training (or equivalent) and working within different health related environments. These events were not always told in the same order, but they were featured in all the interviews. Following this, we analysed how the interviewees position themselves within their stories and over the different periods their stories covered. Moreover, we took into account how they position themselves within the interview situations. They are told by people who have gone through a disruptive life event and now wish to engage with health services as experts. However, their position within health services is not fully established and their claims to expertise are not always recognised (Jones & Pietilä 2018). During the interviews, the participants often

emphasised their expertise and knowledge, portraying themselves as capable and competent. Hence, the interview situations were partially seen as opportunities to present oneself positively and to promote the work done by experts by experience. Due to this, some of the more negative experiences and emotions may not have been expressed during the interviews. Lastly, we explored whether the stories told by the participants about becoming and being an expert by experience have similarities with larger narrative types (described e.g. Frank 1995; Kirkpatrick & Byrne 2009, Martin et al. 2014), as people are often influenced by, and draw from, culturally available narratives when they are telling their personal stories (Ahmed 2013).

## **Results**

We have divided the results into two parts. In the first part, we will explore the process of becoming an expert by experience that includes sharing lived experiences and constructing them into a structured personal account. This process enabled the participants to *re-discover* their expertise by re-connecting with prior skills and combining them with new knowledge. The emergence of this re-discovered identity was deemed necessary by the participants as it formed the basis for the next stage in their stories. The second part focuses on being an expert by experience. In these accounts, the participants construct both *professionalised* and *politicised* identities that allowed them to establish themselves in new working environments and as credible advocates. We also recognise that there were nuances between the stories, as some of the participants were more inclined to seek an established professional role, whereas others described being an expert by experience more in terms of societal action. Despite these differences, the stages of being and becoming as well as the identities described in this section, featured in all the accounts.

### *Becoming an expert by experience and the re-discovered self*

The participants commonly began their accounts by talking about their lives prior and during the acute illness period. They described the disruptions by the illness, such as having to give up work, reduced social contacts, spending time in hospital or experiencing treatment side-effects. Those caring for a family member had experienced losses, feelings of helplessness and they had needed to dedicate much of their

time to understand how to navigate the health and social care systems. During the recovery period, they had found out about expert by experience (or equivalent) training and had decided to apply. Meeting others in a similar situation was described as a significant experience that allowed the participants to reflect and begin to verbalise their experiences. Attending the training sessions provided them with a meaningful activity and an opportunity to work through difficult emotions. Through this process, the participants could also start to construct identities, not as patients or carers, but as experts of their own lives and conditions. In the extract below, Anna has been asked about the training she had attended. She begins by describing the time she attended the first training session:

Anna: *I remember how timid I was, going there for the first time. Although I had performed publicly before and been a trainer, I was at rock bottom, lacking any self-esteem. You could say that it provided a path back into this society and away from complete isolation. It was a turning point when I began to formulate my life story, and that's where all rehabilitation stems from. We started to practice telling our own stories. I felt that I was being treated as an equal and I received admiration and respect, like "wow, you've gone through that".*

In her account, Anna describes how the training had changed the way she felt about herself and her past experiences. The encouragement she received during training and her encounters with others allowed her to transform. During the interviews, the participants emphasised that these encounters with others allowed them to share embodied experiences, compare different ways of coping and navigating health services. Caron-Flinterman et al. (2005) have suggested that through this process, lived experiences can be combined and turned into a collective pool of experiential knowledge. The training process enabled participants to view past life-events as challenges that they had overcome. The participants also highlighted that they had gained ownership of their experiences and re-contextualised them as positive resources. Hence, the illness experience could be interpreted as useful (Frank 1995) or as one of the participants described, "*before the training, psychosis was a really difficult thing, but once I've started this expert by experience work, it's a treat talking to people about it*". As Anna's story above reflects, there was a significant difference in how the participants described their past and present selves. The past selves were

often referred to as isolated, confused or low, whereas the present selves had more self-esteem, knowledge and resources to cope. Like in Tomi's story, the training period was described as a rehabilitative process that provided coherence and a new sense of direction:

Tomi: *The past five years were a dark period in my life. I was at home too much. Not enough social contacts and I began to fear people and life. But becoming an expert by experience has provided me with a set of keys. I can turn the key in a lock and get back into the light. For many, it can be a turn for the better and a reason to go forward in life. When you asked me what it means to me. Well, I would never talk about something like a leather sofa in the same way [as personal experiences]. We're talking about important issues here. The first lecturing jobs [were rewarding for me], since I'd done a lot of acting before, but had to stop because of my illness. I started to enjoy performing again, in a different role of course, but there are similar elements.*

Tomi emphasises that becoming an expert by experience has been personally meaningful for him. He has been able to re-connect with some of the skills he already possessed and he was able to start using them as he took his first steps as an expert by experience. The personal recovery aspect was not as strongly highlighted in the stories told by the participants with caring experiences. However, they also talked about the importance of turning experiences into a structured account and finding value in the skills and knowledge of the care system that they had accumulated. Tomi's story also highlights another common feature of the interviews. During the interviews, the participants wanted to create distance between their past and present selves by emphasising how skillful and capable they had become. Despite the rehabilitative and supportive aspects, the main aim of the training was to prepare the participants for future work. In order to become an expert by experience, the participants were encouraged to construct a clear story, outlining their illness or caring experience. Hence, through practice and feedback, they began to create structured accounts, aimed at wider audiences such as health professionals, policy makers and the general public.

Marko: *The experience is structured for you during the training and you give practice lectures and as you work on it you gain different perspectives. This training is definitely good and a great springboard. The practice lectures give you certainty and following them the trainer says, "you've given three lectures here, how about trying out with an audience?"*

Marko continued to explain that in order to become an expert by experience, one must learn to articulate experiences clearly. Otherwise their message would sound incoherent, like "*porridge*" to outside listeners. The same idea was echoed in the other accounts of the re-discovery phase. The participants wanted to be able to relay their embodied experiences to others, yet emphasised the need to step back and distance themselves from what had happened. They talked about using these structured stories in a multitude of different ways depending on the audience and explained that these stories were tools through which they can "*give hope*" or "*provide an example*" of overcoming challenges. As these structured stories are the main 'tools' experts by experience use in their work, questions arise on whether the training process could reinforce certain forms of illness narratives, such as the restitution and quest narratives that portray the illness as an opportunity for growth and development (Frank 1995). In order to become an expert by experience, the participants needed to show that they had overcome past challenges and were now able to move on, which can potentially marginalise certain narrative types, such as the chaos narrative that "*imagines life never getting better*" (Frank 1995:97). One of the participants, Heidi, directly addressed this issue, recognising that becoming an expert by experience requires proactivity from individuals, which means that those who lack hope and motivation may not become experts by experience. Those who are not willing or able to participate in the process and formulate a story with a clear message may be less likely to participate, which means that more chaotic stories may be less likely to filter through to health services.

Overall, in the stories that outlined the process of becoming an expert by experience, the participants constructed themselves as experts of themselves and their lived experiences. They were able to re-discover strengths and combine what they already knew with their newly acquired knowledge. Despite recognising

some of the challenges related to the training process, this phase was described as a necessary first step that created a foundation for professionalisation and motivated the participants to influence societal issues.

*Life as an expert by experience - the professionalised and politicised self*

Following the initial training and story construction phase, the participants had entered health services and taken on a variety of roles such as peer group leads, members of managerial groups, trainers and developers. The level of involvement varied, as some were more comfortable with occasional work, whereas others actively viewed this as a stepping-stone into a new career. However, the position of experts by experience within health service organisations remains unclear (Jones & Pietilä 2018). Trying to gain acceptance and appreciation in an environment dominated by established professional groups was not easy. Perhaps due to these reasons, the participants emphasised the importance of training “to set personal boundaries and express yourself clearly” and explained how they were constantly educating themselves further. During the interviews, they often listed their training and work experience, with some of the participants even bringing work portfolios to the interviews. In the next extract, Jenni talks about the importance of being trained and possessing professional traits, such as adaptability:

Jenni: *I've participated in the expert by experience training and I am also a trainer. But currently the title is not protected so the service providers can receive varied service if they get an expert by experience who hasn't completed the training. I'm sure some of them are skillful and great people but if you order an expert by experience through us then quality has been verified and the person can manage this type of work. You need flexibility and adaptability to work with in different situations. And you need to adapt your story and your speech so it's not just the same 30 minutes and there are no other versions. Professional skills should be developed further whilst working. [Lists different development and research projects she is involved in currently] I have distance from my experience, so I see things differently. Even staff and*

*doctors can ask me questions that they could not ask a patient. I am not acutely ill, so I can take things differently and I can tell what people might need in those kinds of situations.*

Jenni had been able to establish herself and had created a wide network of contacts. In her story, she emphasises the importance of training, skills and continuous development. Jenni argues that she has successfully left the raw illness experience behind and is no longer a patient, but a fellow 'professional' able to work in a multitude of specialist roles. Indeed, those who were actively engaged in involvement activities expressed that they wanted experts by experience to be seen as a legitimate participant group or even a 'professional title'. Those who lacked the correct 'qualifications' were not always considered legitimate experts by experience and their ability to participate could be questioned.

The illness had prevented many of the participants from returning to their previous profession. However, as experts by experience, they could return to work at least part time and in some cases to similar working environments as before. Four of the participants held health or social care qualifications and this 'dual-qualification' they now possessed enabled them to reconnect with their previous knowledge and skills and combine them with their experiences. In the following extract, Katri talks about the transition back into work following the training:

Katri: *I just finished my expert by experience training last April. I was selected to the management group and then the opportunities have arisen from that, like getting to work in partnership with a nurse in the acute services. I've got a background in health care, working as a specialist nurse in an operating theatre and in the acute service. So I've been able to continue that kind of work.*

Some of the participants without a 'dual-qualification' had been motivated to educate themselves further and gain health professional qualifications in a field such as therapy or substance abuse work. One of the participants explained that his new degree "*provides more credibility in these working groups and projects*". Additionally, the participants sought information from a number of sources, which enabled them to

become highly specialised in their self-proclaimed fields of expertise. Every time the experts by experience participated in involvement activities, their knowledge and networks expanded. Professionals and managers then requested them to participate in new projects, many of which required specialist knowledge of the health care system, care pathways and complex needs. Although working within health services could be demanding, it was predominantly described in positive terms.

Leena: *At the first meeting when I introduced myself, I said that I'm not quiet and I'm here to get noticed. So from the start they were like "ok". Some were a bit suspicious at first, questioning whether I understood what's going on or knew what I'm talking about. But respect must be earned and very quickly I was a full-fledged member of that group.*

Much like Katri's seemingly smooth transition back into work, Leena's story is also that of success. She was able to triumph despite being met with suspicion. This was a common feature in all the accounts of working in professional setting. Some of the stories contained descriptions of health professionals doubting or belittling the experts by experience. However, these accounts often ended with the expert by experience becoming an accepted participant. The participants made small references to other experts by experience, who had not been as successful and had no longer been invited to managerial groups or offered new work opportunities. This can indicate that the acceptance of experts by experience is still largely reliant of professional approval. Those who are able to establish themselves needed to balance between being critical and able to compromise. This created some tensions in the construction of the professionalised self, as the participants wanted to ensure that they could also voice criticism. As one of the participants expressed it, experts by experience wanted to be legitimate collaborators without becoming "poodles" who uncritically accept the agenda set by others.

Entering health services as experts by experience was also a signal that the participants had 'moved on' with their life, stepping further away from the personal. However, working within health services and developing them from within was not the only path available for experts by experience. The process of re-discovery had provided the participants with an opportunity to compare experiences and uncover collective

grievances. They were able to draw from embodied and social experience and make the personal political. Some of the younger participants identified themselves firstly as “*mental health activists*” and they drew ideas for action from shared collective experiences. In the following extract, Heidi explains her motivation for becoming involved with a group of experts by experience and combining her personal experience with the experiences of others to “*change things*”.

Heidi: *When I got involved, I thought that I've got difficult experiences and the care system has not worked at all for me. I was not cared for and I could see a lot of problems. I wanted to do something to change things. We meet every two weeks and talk about what we want to do. We had this idea for a board game that would demonstrate what it's like to live in this system. During the game you wander around and the game instructors give you guidance and tell you the rules, but the players get into situations where they really don't know what to do and there are all these barriers that prevent you from getting where you want to go. We've developed this game based on experiences gathered from lots of people.*

Heidi and the other group members gave lectures and they had created a game, which they played with professionals and policy makers. By using their lived experiences, they wanted to highlight the barriers that people with mental health problems can face in their daily lives. The socially and politically motivated activities could take on several forms, such as the promotion of experiential knowledge and challenging stigma by telling one's story in the media. A group of experts by experience had formed their own organisation that was trying to provide practical guidelines for experiential work and promote a clearer pay structure. Additionally, they shared information about ongoing training around the country, answered queries and acted as a point of contact for organisations who wanted to employ experts by experience. After her training, Jenni had joined the organisation, worked in a number of different involvement projects and had taken on an active role promoting expertise by experience in the media:

Jenni: *This [work of experts by experience] has been raised into public discussion. I have been in charge of communication [for an expert by experience organisation] and worked hard to make this a more visible phenomenon in Finland. Maybe that has helped. I don't get paid for*

*it, but I've really enjoyed that I get to do this and bring about some change. Some people may think that this is challenging and opens up old wounds. But I know how to stay within my own comfort zone even when I talk about terrible things that have happened to me. I'm at peace with it.*

Jenni emphasises that she has processed her experiences and is now able to advocate for others. She describes her work almost in terms of a calling. However, advocating for others in this very public way turned experts by experience into the public faces of illness and caring experiences. Sharing their stories in newspapers, magazines and TV shows was described as an integral part of being an expert by experience. Nevertheless, it also created some tensions:

Leena: *When you open yourself up, you have to be careful where to draw the line. Do you say 'my father' or do you say 'this one man'. There's a difference. And you have to remember that Finland is a small country. If you don't know how to draw boundaries then you can tire yourself out pretty quickly. Sure it's flattering at first when you're asked for interviews and lectures. It would be flattering to anyone and that's normal. But what surprised me is that they wanted to know much more than what I was willing to share.*

When Leena was asked to share some of the challenges she had faced as an expert by experience, she talked about her experiences with the media and how she had to learn to set boundaries to protect her privacy. Although the illness accounts shared were personal, they often included other people and the participants needed to decide whether or not to share information relating to family members. Leena had been an expert by experience for several years and in the extract she presents herself as reflexive and capable of staying in control, even in challenging situations. The worry about oversharing and becoming a face of illness experience was also raised by one of the younger participants, as she wondered whether her openness would backfire if she applied for a job outside of experiential work. Overall, issues around stigma were addressed in all the interview accounts.

In the stories, politicisation and professionalisation processes co-existed and even fed into each other as the participants gained more knowledge, skills and self-assurance from working both within and without health services. Overall, the decision to become an expert by experience had provided the participants with opportunities to process their own experiences and then enabled them to reconstruct a story that did not focus merely on personal recovery or health service improvement, but wider social and attitude change. A common feature of these stories about life as an expert by experience was their positive tone. Indeed, the participants expressed that they felt proud of their work and were happy about the direction their life had taken after a difficult period. However, they may also feel the need to present a positive image of themselves and the work of expert by experience in order to promote it and ensure that their involvement continues to be supported.

## **Discussion**

In this article, we have explored stories told by people with lived illness and caring experiences about the process of becoming and being an expert by experience. Based on our findings, we argue that the process of becoming provides opportunities for people to re-contextualise their past experiences, *re-discover* their skills and begin to construct *professionalised* and *politicised* identities. We also claim that the process of becoming an expert by experience can influence the way in which lived experiences are structured and presented. We will now discuss these findings in more depth and relate them to prior research on involvement and experiential expertise.

Thompson et al. (2012) have claimed that patient and public involvement “can provide opportunities for those involved to reconstruct reflexively positive subject positions based on their involvement and the acquisition of skills, knowledge and experience” (p. 617). Additionally, Rissanen (2015) has highlighted how the process of becoming an expert by experience can act as a stepping-stone into new opportunities. Our findings support these ideas, as the participants of this study expressed that sharing and verbalising experiences had supported their recovery. They also highlighted that the process of becoming an expert by

experience had strengthened their self-esteem and reminded them of all the knowledge and skills they possessed. However, their stories also suggested that as a prerequisite for involvement, people need to become experts of themselves (Meriluoto 2017). During the training, they are expected to disclose personal experiences and to distance themselves from them. Indeed, Näslund et al. (2019) has suggested that people with lived experiences need to learn how to tell stories that convey vulnerability and resonate with listeners on an emotional level. Nevertheless, it needs to be told in a manner which shows that the narrator is in control of their story and emotions (Näslund et al. 2019). This was also advocated by our participants as they emphasised the importance of distancing themselves from the personal and constructing a clear, coherent account of their lived illness and caring experiences. According to the participants, this was done for two reasons. Firstly, they wanted to retain a sense of control, which meant deciding what to share and what to keep private. On a personal level, the construction of a structured account can provide coherence to past events and help to build a positive sense of self (Lysaker et al. 2010). Secondly, the participants expressed that the information and knowledge they shared with health services needed to be polished and structured. This may create pressure on the experts by experience to structure and present their experiences in ways that health professionals and health services find acceptable and relatable (Jones 2018). If the accounts are incoherent or difficult for the audience to understand, then they may not be regarded as 'fit for purpose'. Hence, the participants needed to make active choices about what they share and how they share their experiences. Based on these findings, we suggest that processing and constructing an account of past experiences may influence how past experiences are articulated. If the personal account needs to be neat and structured, then narrative types that lack coherence or imagine life never getting better (e.g. chaos narrative, Frank 1995) may not fit in with the ethos.

Whereas the re-discovery phase focused inwards, providing a meaning-making framework and preparation for the future, the politicised and professionalised identities directed activities towards health services and the wider society. Although our participants recognised some of the challenges and tensions associated with becoming an expert by experience, their stories were largely positive in tone, highlighting how the

participants had overcome adversities. Hence, the stories about being an expert by experience often followed a similar form to Frank's (1995) quest narrative, which portrays the illness experience as a motivator for social action or change or even an automythology in which the illness experience reveals a new destiny. For our participants, the illness experience became a stepping stone that allowed them to become experts by experience, re-connect with old skills, return to work and discover issues in society or the care system that they wanted to change. Additionally, working within health services could be an empowering experience and a signal that the participants were '*moving on*' (Martin et al. 2014). However, we also acknowledge that during the interviews the participants were not only providing accounts of their experiences and activities, but also advocating for the increased involvement of experts by experience. Additionally, they were familiar with the stigma and negative perceptions associated with people who have experienced mental illness. Perhaps due to these factors, they wanted to present themselves as capable and knowledgeable, and to construct identities that highlighted how active and skilled they were.

When describing their work as experts by experience, the participants no longer referred to themselves as patients or carers, but as educators, developers and service producers. They talked about the importance of specialist skills and knowledge that often exceeded personal experience and were continuously educating themselves further. Indeed, being interested appears to be an integral part of being involved and lay participants often draw from their experiential, cultural, social and relational resources as they become engaged with involvement activities (Lehoux et al. 2012). However, the patient and public involvement imperative has made it possible, and perhaps even necessary, for the participants to seek a more professionalised position within environments where established professional groups have traditionally been the decision-makers. Our findings suggest that involving lay participants more actively in health services may lead to them pursuing a more professionalised role and status. Unlike the interviewees in Maguire and Britten's (2018) study, who emphasised their '*layness*', our participants tended to emphasise their specialist expertise and qualifications. This may lead to the development of hierarchies among the '*lay participants*'. As El Enany et al. (2013) have argued, a segment of articulate participants who pursue a

professional status can lead to the creation of a distinct body of 'experts' and exclude others that are considered as 'less expert'. Additionally, some of our participants formed an interesting sub-group for they possessed a 'dual-qualification'. In other words, they were trained as experts by experience and had professional training. This group of participants can blur the lines between lay and professional even further. As experts by experience, they had been able to re-enter the health services as experiential workers. They also had the additional benefit of understanding the norms, structure and terminology of health services, which could benefit their work prospects. However, even their stories highlighted that experts by experience were required to prove themselves in the eyes of the established professionals.

Prior studies have questioned whether patient activism can continue to exist alongside the professionalised self (Lakeman et al. 2007). Although there were tension associated with adopting a professionalised identity, the participants appeared to combine the professionalised and politicised identities. This suggests that being an expert by experience is not only about influencing health services, but includes elements of activism and advocacy. Much like the expertise by experience in Noorani's (2013) study, the politicised self was based on authority and expertise that stemmed from collective meaning-making and connecting of experiences. Personal and collective experiences were gathered and verbalised by experts by experience and used to highlight problems, grievances and criticism. However, making the personal political meant giving up some privacy for being an expert by experience often included sharing personal experiences publicly.

In this study, we have focused on the process of becoming and being an expert by experience. However, we acknowledge that our interviewees represent a group who have managed to secure a position as participants. They wanted to have a critical stance, but chose to actively collaborate and forge a working relationship with health professionals. Hence, these are stories told by people who have been successful in their attempts to become experts by experience. Those who have completed the training but have not been as successful integrating into health services may tell different stories, which are equally worth

exploring. Overall, our findings highlight that becoming involved in health service development and delivery can be a transformative and meaningful experience. Nevertheless, as more people are trained to become experts by experience, attention needs to be paid to the content of the training, the ways in which lived experiences are processed and the potential stratification that the training requirement can create among lay participants.

## References

- Ahmed, A. (2013) Structural narrative analysis: Understanding experiences of lifestyle migration through two plot typologies. *Qualitative Inquiry*, 19, 3, 232–243.
- Bamberg, M. (1997) Positioning between structure and performance. *Journal of Narrative and Life History*, 7, 1-4, 335-42.
- Bamberg, M. (2006) Stories: big or small – why do we care? *Narrative Inquiry*, 16, 1, 139-47.
- Bamberg, M. (2011) Who am I? Narration and its contribution to self and identity. *Theory & Psychology*, 21, 1, 3-24.
- Bell, K. (2014) The breast-cancer-ization of cancer survivorship: implications for experiences of the disease. *Social Science & Medicine*, 110, 56-63.
- Bherer, L. & Breux, S. (2012) The diversity of public participation tools: complementing or competing with one another? *Canadian Journal of Political Science*, 45, 2, 379-403.
- Bury, M.R. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4, 2, 167-182.
- Byrne, L., Happell, B. and Reid-Searl, K. (2016) Lived experience practitioners and the medical model: world's colliding? *Journal of Mental Health*, 25, 3, 217-223.
- Caron-Flinterman, F.J., Broerse, J.E.W. and Bunders, J.F.G. (2005) The experiential knowledge of patients: a new resource for biomedical research? *Social Science & Medicine* 60, 2575-2584.
- Charmaz, K. (2000) Experiencing chronic illness. In GL Albrecht, R Fitzpatrick & SC Scrimshaw (Eds.) *Handbook of social studies in health and medicine*. Sage: London.
- De Fina, A. (2013) Positioning level 3: connecting local identity displays to macro social processes. *Narrative Inquiry*, 23,1, 40-61.

- Dent, M. and Pahor, M. (2015) Patient involvement in Europe – a comparative framework. *Journal of Health Organization and Management*, 29, 5, 546-555.
- El Enany, N., Currie, G. and Lockett, A. (2013). A paradox in healthcare service development: Professionalization of service users. *Social Science & Medicine*, 80, 24-30.
- Frank, A. (1995) *The wounded storyteller: body, illness and ethics*. Chicago: University of Chicago Press.
- Grant, A., Leigh-Phippard, H. & Short, N.P. (2015) Re-storying narrative identity: a dialogical study of mental health recovery and survival. *Journal of Psychiatric and Mental Health Nursing*, 22, 278-286.
- Hirschovits-Gerz, T., Sihvo, S. Karjalainen, J. & Nurmela, A. (2019) *Kokemusasiatuntijuus Suomessa: selvitys kokemusasiatuntijakoulutuksen- ja toiminnan käytännöistä*. Helsinki: THL.
- Jones, M. (2018) Kokemustiedon määräykset ja käyttö julkisen terveydenhuollon kontekstissa. In: Toikkanen, J. & Virtanen, I.A. (eds.) *Kokemuksen tutkimus VI: kokemuksen käsite ja käyttö*. Rovaniemi: Lapland University Press. pp. 169-190.
- Jones, M. & Pietilä, I. (2017) “The citizen is stepping into a new role”—Policy interpretations of patient and public involvement in Finland. *Health and Social Care in the Community*, 26, 2, e304-e311.
- Jones, M. & Pietilä I. (2018) Alignments and differentiations: People with illness experiences seeking legitimate positions as health service developers and producers. *Health*, DOI: 10.1177/1363459318800154
- Kelly, M. (1994) *Coping with chronic illness: a sociological perspective*. Inaugural lecture, University of Greenwich.
- Kirkpatrick, H. (2008) A narrative framework for understanding experiences of people with severe mental illnesses. *Archives of Psychiatric Nursing*, 22, 2, 61-68.
- Kirkpatrick, H. and Byrne, C. (2009) A narrative inquiry: moving on from homelessness for individuals with major mental illness. *Journal of Psychiatric and Mental Health Nursing*, 16, 68-75.
- Lakeman, R., McGowan, P. and Walsh, J. (2007) Service users, authority, power and protest: A call for renewed activism. *Mental Health Practice*, 11, 4, 12-16.
- Landry, D. (2017) Survivor research in Canada: ‘Talking’ recovery, resisting psychiatry, and reclaiming madness. *Disability & Society*, 32, 9, 1437-1457.

- Lehoux, P., Daudelin, G. and Abelson, J. (2012) The unbearable lightness of citizens within public deliberation processes. *Social Science & Medicine*, 74, 1843-1850.
- Lysaker, P.H., Ringer, J., Maxwell, C., McGuire, A. and Lecomte, T. (2010) Personal narratives and recovery from schizophrenia. *Schizophrenia Research*, 121, 271-276.
- Maguire, K. & Britten, N. (2018) 'You're there because you are unprofessional': patient and public involvement as liminal knowledge spaces. *Sociology of Health & Illness* 40, 3, 463-477.
- Martin, L.A., Moye, J., Street, R.L. Jr. and Naik, A.D. (2014) Reconceptualizing cancer survivorship through veterans' lived experiences. *Journal of Psychosocial Oncology*, 32, 3, 289–309.
- Meretoja, H. (2018) *The ethics of storytelling: narrative hermeneutics, history, and the possible*. New York: Oxford University Press.
- Meriluoto, T. (2017) Turning experience into expertise: technologies of the self in Finnish participatory social policy. *Critical Policy Studies* 12, 3, 294-313.
- Ministry of Social Affairs and Health (2009) *National mental health and substance abuse plan 2009-2015*. Retrieved from: [www.stm.fi](http://www.stm.fi).
- Ministry of Social Affairs and Health (2018) *Mielenterveys- ja päihdepalveluita uudistetaan kokemusasiantuntijoiden avulla* [Mental health and substance abuse services are developed with experts by experience]. Retrieved from: [www.stm.fi](http://www.stm.fi).
- Nielsen, E., Myrhaugh, H., Johansen, M., Oliver, S. and Oxman, A. (2013) Methods of consumer involvement in developing health policy and research, clinical practice guidelines and information material. *Cochrane Database of Systematic Reviews*, 19, CD004563.
- Noorani, T. (2013) Service user involvement, authority and the 'expert-by-experience' in mental health, *Journal of Political Power*, 6, 1, 49-68.
- Nunes, J. and Simmie, S. (2002) *Beyond crazy: journeys through mental illness*. Toronto, Canada: McClelland & Stewart Ltd.

Näslund, H., Sjöström, S. & Markström, U. (2019) Service user entrepreneurs and claims to authority – a case study in the mental health area. *European Journal of Social Work*, 1-13, 10.1080/13691457.2019.1580249.

Prime Minister's Office (2015) *Finland, a land of solutions. Strategic Programme of Prime Minister Juha Sipilä's Government*. Helsinki: Government Publications.

Reynolds, F. (2003) Reclaiming a positive identity in chronic illness through artistic occupation. *OTJR: Occupation, Participation and Health*, 23, 3, 118–127.

Rissanen, P. (2015) *Toivoton tapaus? Autoetnografia sairastumisesta ja kuntoutumisesta*. Helsinki: Kuntoutussäätiön tutkimuksia 88/2015.

Thompson, J., Bissell, P., Cooper, C., Armitage, C.J. and Barber, R. (2012) Credibility and the 'professionalized' lay expert: reflections on the dilemmas and opportunities of public involvement in health research. *Health*, 16, 6, 602-618.

Toikko, T. (2016) Becoming an expert by experience: an analysis of service users' learning process. *Social Work in Mental Health*, 14, 3, 292-312.

### **Acknowledgements**

We are grateful to the participants who took part in this study and shared their stories about becoming experts by experience. We would also like to acknowledge and thank the three anonymous reviewers for their valuable guidance and constructive comments.