



Experts by experience education and presence online - a descriptive literature review

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2022 Laurea





Laurea University of Applied Sciences

**Experts by experience education and presence online -
a descriptive literature review**

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Degree Program in Social Services
Bachelors thesis

Toukokuu 2022

Laurea-ammattikorkeakoulu
Degree Program in Social Services
Sosionomi AMK

Tiivistelmä

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Experts by experience education and presence online - a descriptive literature review

Vuosi 2022 Sivumäärä 33

Vuonna 2020 maailmanlaajuinen koronapandemia pakotti ihmiset ottamaan fyysistä etäisyyttä ja sulkemaan oppilaitoksia ja koulutusohjelmia. Etäisyyden ottamisen vuoksi täytyi opetus ja oppiminen yllättäen järjestää suurelta osin verkossa.

Tämän opinnäytetyön tarkoituksena on tutkia minkälaista tutkimusta oli tehty kokemusasiantuntijuudesta ja verkko-oppimisesta sekä verkkotoiminnoista. Opinnäytetyön tilasi Kokemusasiantuntijat verkossa-hanke, jonka tarkoituksena on lisätä kokemusasiantuntijoiden osaamista ja työllistymismahdollisuuksia, sekä vastata verkkoauttamisen tarpeeseen. Opinnäytetyön teoreettinen viitekehys koostuu osallisuuteen, vertaistukeen ja oppimiseen liittyvistä käsitteistä.

Opinnäytetyössä käytettiin menetelmänä kuvailevaa kirjallisuuskatsausta ja sen tavoitteena oli vastata tutkimuskysymyksiin liittyen kokemusasiantuntijoiden toimintaan verkossa ja verkko-oppimiseen sekä keinoihin, joilla voi edistää kokemusasiantuntijoiden verkko-oppimista ja osallisuutta. Kirjallisuuskatsaukseen valikoitui yhdeksän artikkelia kuudesta eri tietokannasta. Materiaali analysoitiin sisältöanalyysiä käyttäen.

Kirjallisuuskatsauksen tulokset olivat moninaiset, ja tämä myös osaltaan kuvasi kokemusasiantuntijan monipuolista roolia. Tulokset osoittivat, että kokemusasiantuntijoille räätälöidyistä verkkokoulutuksista oli pulaa ja heiltä saattoi puuttua itseluottamusta, taitoja ja työkaluja verkkotoimintaan. Useissa artikkeleissa ehdotettiin kohdennettuja ratkaisuja verkkopalveluiden käyttäjille sekä vaivatonta pääsyä verkkopalveluihin, joilla voidaan ehkäistä kokemusasiantuntijoiden digitaalista syjäytymistä.

Asiasanat: kokemusasiantuntija, vertaistuki, verkko-oppiminen, digitalisaatio, osallisuus

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Year

2022

Pages

33

In 2020 the COVID-19 pandemic quickly shut down schools and education programs, which in turn forced new ways of teaching and learning, moving a majority of studies online.

The purpose of this thesis is to explore what has been written about experts by experience and online learning. The thesis was commissioned by the Kokemusasiantuntijat verkossa-project, which aims to improve experts by experience digital skills and employment opportunities. The project also aims to respond to the current need of online counselling. The theoretical framework of the thesis consists of concepts around inclusion, peer support and learning.

The thesis used descriptive literature review as the method, and its aim was to answer questions about experts by experience online presence and the action, which could be taken to promote inclusion with experts by experience. A total of nine articles were retrieved from six different data bases, and the data was then analyzed using content analysis.

The results were varied, also portraying the fluid role of an expert by experience. The results show that there was a lack of bespoke training for experts by experience and they often lacked skills, confidence and often tools for online activities. Many of the articles pushed for more tailored solutions for all service users and called for an easier access for internet-based learning and training to prevent further digital exclusion amongst experts by experience.

Keywords: experts by experience, peer support, online learning, digitalization, inclusion

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1 Introduction

Expert knowledge is widely used together with professional and scientific knowledge and information. We are all guided by experiences in our everyday life. They say: "everyone is an expert in their own life", which emphasizes that no one can fully understand or know the other person's experiences, or "walk in their shoes". Individuals are guided by past experiences when it comes to making decisions or choices in their lives. Knowledge and know-how based on expert experience can be used in gaining a better understanding of what an individual is going through. The expert experience can also be used in using available services and in peer support, peer work and peer counselling (Hirschovits-Gerz, Sihvo, Karjalainen and Nurmela 2019).

Experts by experience is a form of peer support, which was developed in the 21st century. It is based on using one's past experiences to help others to cope with similar issues. The trained experts by experience are or have been dealing with mental health or substance abuse problems or are loved one's of people with mental health issues or substance abuse problems (THL 2022).

My thesis stems from a need for a literature review to establish what has been written about experts by experience, specifically studying and working remotely and with online tools to be able to ensure that, in the future, there will be better career opportunities for experts by experience by strengthening their online skills and the use of remote learning and working tools.

2 Background

This chapter will introduce the phenomenon's connected to this thesis. The effects of the virus and social distancing has brought great adjustments to the way we learn and study. Due to the effects of the pandemic a great number of studies moved online, and even though the world is slowly getting back to normal, studying online has partly become the new norm. COVID-19 has also had an impact on experts by experience due to the new learning environments.

2.1 Effects of the Covid-19 pandemic

Coronaviruses is a group of common viruses that usually cause a mild respiratory tract infection on human. However, in December 2019 an epidemic broke out in Wuhan, China, which was caused by novel coronavirus in humans. The disease caused by the new virus was officially named COVID-19. The pathogen virus has been named SARS-CoV-2. The World Health Organization declared the epidemic as a global pandemic on 11th March 2020 (Terveyskirjasto 2022). As a result

of the ongoing pandemic, people have had to retreat to their homes, and practice social distancing in order to protect themselves and others from spreading the virus.

”The COVID-19 outbreak affects all segments of the population and is particularly detrimental to members of those social groups in the most vulnerable situations, continues to affect populations, including people living in poverty situations, older persons, persons with disabilities, youth, and indigenous people. If not properly addressed through policy the social crisis created by the COVID-19 pandemic may also increase inequality, exclusion, discrimination, and global unemployment in the medium and long term.” (United Nations 2022.)

2.2 Online learning

Since March 2020 students worldwide have had to practice online learning, at least for a period. Practical work cannot be done online, and teachers as well as students have had to find new ways to teach and to learn. It was discovered that the students, who excelled in online learning were the ones who found school easy in a normal learning environment; the ones who could divide their time between school, free-time and sleep and who were able to set goals and follow them through. Online learning was especially difficult for the students, who found studying hard in general. Online learning has caused lack of motivation and increase of stress in students (Valkonen 2020). The disruption in education and learning caused by the pandemic could have consequences, medium and long-term, on the quality of education (United Nations 2022). To be more inclusive during the changing times, the education systems need to transform, making sure the technology is to benefit all levels of learners (Unesco 2022).

2.3 KEIJO project and experts by experience online project

KEIJO stands for ”kokemusasiantuntijuus edistämässä itsenäisyyttä ja osallisuutta”. It translates loosely as ”experts by experience in promoting independence and inclusion”. KEIJO project was a co-operation project by Valo-Valmennusyhdistys together with Silta-Valmennusyhdistys and Laurea University of Applied Sciences.

KEIJO project (2018-2020) in Laurea University of Applied Sciences trained experts by experience with a history of prison sentences or substance abuse problems. Over a half of the trained experts by experience are now in working life or further studies. The good results of the project were largely due to the peer support in contact teaching as well as face-to-face support and the possibility for working placements happening in person. As Covid-19 pandemic continued, the experts by experience studies moved more and more online, and significantly decreased the career opportunities and led to reduced ability to function.

Global pandemic COVID-19 has brought more challenges to the learning and training process of experts by experience. Many recovering addicts and ex-prisoners have limited skills to work

online and use different tools. Motivation might also be lacking. Laurea University of Applied Sciences has launched a multidisciplinary project called "Experts by experience online" due to the corona pandemic and changing needs and skills. As the pandemic is still going on there are new needs for strengthening digital skills, developing online counselling knowledge and methods, and skills that are related to reaching out to various target groups and participating in online counselling (Valo-valmennusyhdistys ry 2022).

3 Theoretical framework

In this next section I will be introducing the theoretical framework of my thesis. This will enlighten the concepts that I have used while conducting my search process.

3.1 Inclusion

Inclusion is defined as being involved, influencing, care and being a part of well-being built together (STM 2022). Advancing inclusion has been named as one of the targets of both, the Finnish government and the European Union. By promoting inclusion, we can reduce inequality as inclusion is a premise of health and equality. Participation is one way to inclusion and helps getting involved in a community. There is also a connection between the level of taking part and the individual's socioeconomical position, where the less educated are less involved (THL 2022).

Ways to support inclusion in a society include ensuring a safe, unobstructed living environment and using peer support and experts by experience in creating customer-oriented and multicultural operating models. It is also essential to offer the tailored and adequate support and provide varied education and offer opportunities to people in all socioeconomical groups (THL 2022).

In the midst of difficult times, we need support to increase inclusion and advance our abilities for decision-making. To be included one must be an active participant in their own life. Sometimes there are challenges in life, such as health issues and loneliness can make life seem insignificant. Sometimes all one can do is survive from day to day. In addition to strengthening, one's own personal resources it is important to ensure that there are different ways for an individual to participate in a society. Inclusion can be increased by facilitating access to employment and acknowledging the needs of marginalized groups and minorities and ensuring a safe living environment for all (Soste Ry 2022).

3.2 Rehabilitation

Rehabilitation is defined as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" (WHO, 2022.)

Rehabilitation is a planned process which is based on the individual needs and goals of the rehabilitator. The aim of rehabilitation is to promote the rehabilitator's ability to function and to live independently, their opportunities to participate, work and study skills as well as opportunities of employment and maintaining working life (STM, 2022).

3.3 Peer support

Peer support is sharing experiences with someone, who has gone through the same thing as another person. Peer support is support, which is based on experiential knowledge, and the most important elements of peer support are talking and listening. When an individual is going through a hard time, becomes ill or is recovering, they want information. This information can be gained through professionals and literature, but also through peers. The value of peer support is the mutual understanding and the shared experience (Terveyskylä, 2022).

There is peer support groups and functions for a wide variety of life situations and conditions, starting from AA (Alcoholics Anonymous) and NA (Narcomaniacs Anonymous) to groups for people, who have gone through custody proceedings, groups for immigrants and for different illnesses, mental health disorders and ex-offenders (Nieminen & Lahikainen 2021).

Peer support can be individual, or group based. The groups can be open for all or alternatively closed. Closed groups require regular participation to the group sessions. Peer groups can be led by trained peers, social or health care professional or the groups can be run without a leader. There are peer support groups operating online and in social media (Terveyskylä 2022).

3.4 Experts by experience

Experts by experience is a form of support, which was developed in the 21st century and is based on people's experiences in coping with issues. Experts by experience in mental health or substance abuse fields are trained professionals, who have personal experience in the previously mentioned issues and the services available. Experts by experience might be in recovery, or the issues could be ongoing (THL 2022).

Having said that, Hietala & Rissanen state that expert by experience should have enough personal resources and they should be far enough in their own recovery. On the other hand, acting as an expert by experience can be rehabilitating and empowering (2015, 12).

Improving services, increasing inclusion and the understanding of for example addiction and recovery, changing attitudes, societal influencing and supporting rehabilitation are among the aims of the experts by experience. Their tasks vary from peer supporting and group councillor to developing, influencing, and working alongside of a social care professional (THL 2022).

4 The aim and purpose of thesis and the research questions

The purpose of this thesis is to discover answers to the research questions set by exploring existing research on the subject. The aim is to find out about the pre-existing online presence and remote learning experiences of experts by experience.

I have established the following research questions:

1. What kind of experiences have experts by experience had with online presence and learning?
2. What could be done to further the online learning skills and inclusion of experts by experience online?

5 Methodological approach: Literature review

Literature review is my chosen method for this thesis. According to the general characterization, a literature review is a method and a research technique that examines the previously done research, "research on research". It is the compilation of research results which are a basis for new research findings (Salminen 2011). Literature review is integral when forming a big picture on a specific subject or area of interest (Stolt, Axelin & Suhonen 2015, 6). "In short, literature review is the comprehensive study and interpretation of literature that relates to a particular question" (Aveyard 2019, 2.) A completed literature review is not merely a list or a brief summary of the findings, or descriptions of studies. Instead, literature review offers critical discussion on the topic while also identifying differences and similarities in already existing literature (Salminen, 2011).

The aim of a literature review is to develop the theoretic understanding and concept of a particular discipline. Furthermore, the aim of a literature review can be to recognize contradictions or problems with the chosen phenomenon (Stolt et al. 2015, 7). Reviewing existing literature is important, as the findings can enhance professional development, represent an important scientific contribution, or facilitate the development of practice guidelines, for example (Rhoades 2011).

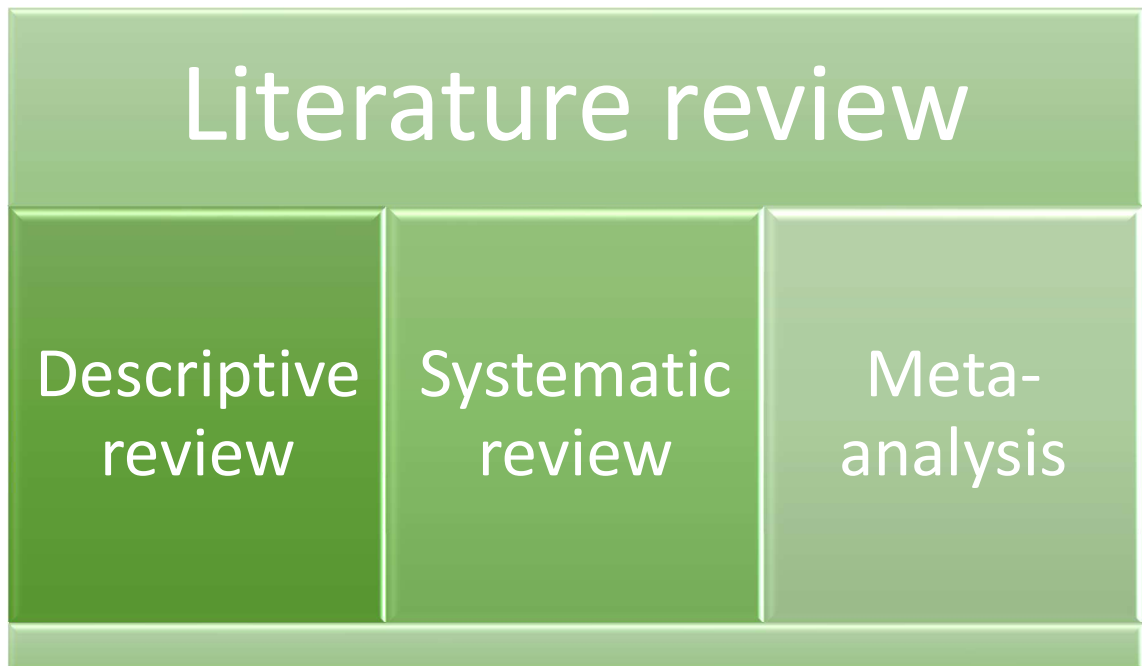


Figure 1. The three forms of literature review (According to Stolt et al. 2015)

There are three main types of literature reviews: descriptive reviews, systematic reviews, and meta-analysis (Stolt et al. 2015, 8). Meta-analysis can be divided into 2 main approaches: qualitative and quantitative (Salminen 2011). The most detailed type of literature review is systematic review, which” aims to identify and track down all the available literature on a topic, while describing a clear, comprehensive methodology.” (Aveyard 2019, 9).

I have chosen descriptive review as a method for my thesis. Descriptive literature review is one of the most used review types. It can be described as an overview without strict and precise rules. The materials used are extensive and the research questions are looser than in a systematic review or meta-analysis. Furthermore, the phenomenon being studied can be described broadly and the qualities of the studied phenomenon can be classified as required. The descriptive literature review works as an independent method, it can also be considered to create new phenomena to be studied in a systematic literature review (Salminen 2011, 6).

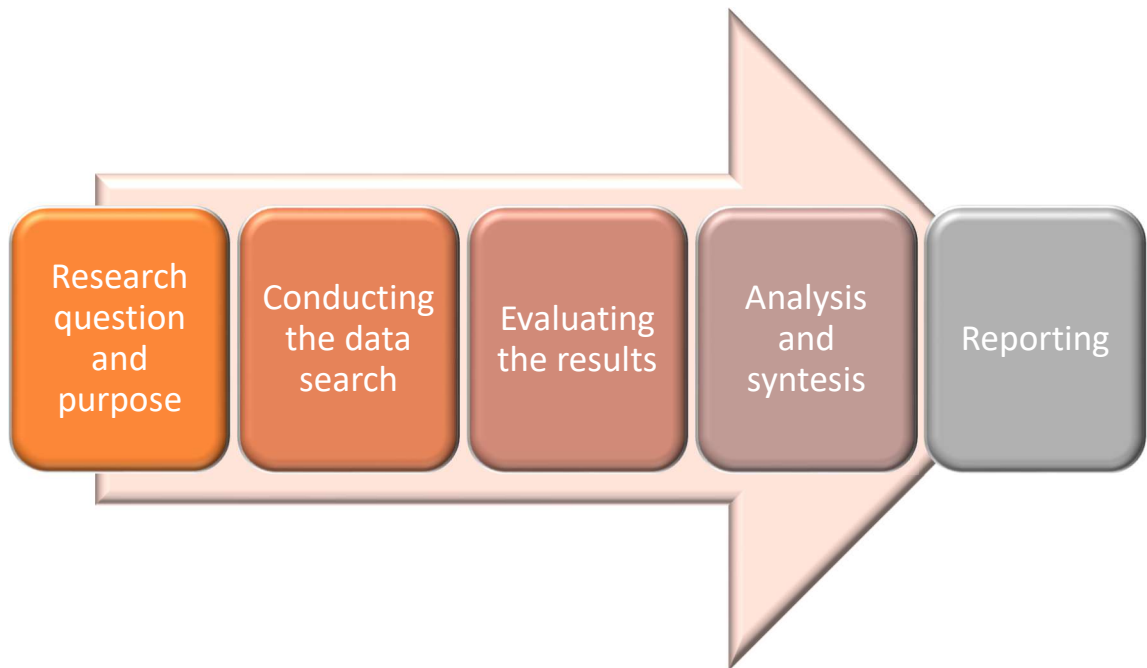


Figure 2. The five stages of literature review (According to Stolt et al.)

Literature review consists of five necessary stages: determining the research question and the purpose of the review, conducting the data search, evaluation of the results, analysis, synthesis, and reporting (Stolt et al. 2015, 23).

5.1 Inclusion and exclusion criteria

The inclusion and exclusion criteria are shown in the below figure 3.

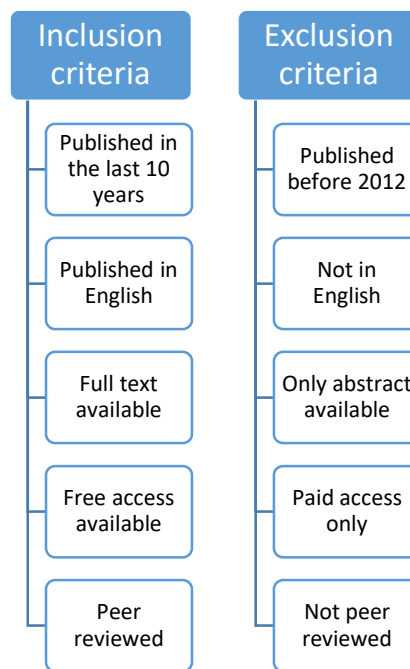


Figure 3. Inclusion and exclusion criteria

5.2 Search process

I first searched with the following combinations of search words: "Experts by experience" OR "lived experience" AND "online learning" OR "online" OR "remote" OR "remote studies" AND "covid-19" OR "pandemic" OR "corona". I soon realised that there would not be enough articles written yet about experts by experience during the pandemic. After discussing with my advisor, I decided to broaden my search to include experts by experience and online or remote learning. Next, I searched with "experts by experience" AND "online" OR "remote" and did not get matching articles. I modified the search to include "education" with "experts by experience"

After testing out several different search words and combinations and establishing the final inclusion and exclusion criteria, I conducted my data search on the 16th of April 2022. All data was electronically collected from six different databases. The databases used were Science Direct, SAGE, ProQuest Central Google Scholar Finna and EBSCOhost combined. Access was provided by Laurea University of Applied Sciences, apart from Finna and Google Scholar, which offer free access to all. The databases were selected on the recommendations on the guidance session on literature review as a method, and the Laurea LibGuides page. Due to the broad search terms and the results of the preliminary searches my main search terms "experts by experience" and "education" resulted in varied amount of adequate hits. The initial search returned altogether 420 results. An additional search was conducted on the 22nd of

April with search terms "experts by experience" AND "digital exclusion", after coming across "digital exclusion as a term during the first data search. This brought the number of initial results up to 498. (Table 1.)

| DATABASE | SEARCH TERMS | EXCLUSION & INCLUSION | RESULTS | APPROVED BY ABSTRACT | ARTICLES READ | APPROVED FOR THE REVIEW |
|----------------|---|---|---------|----------------------|---------------|-------------------------|
| SAGE | "EXPERTS BY EXPERIENCE" AND "EDUCATION" | FULL ACCESS, FREE ACCESS, WITHIN THE LAST 10 YEARS | 22 | 6 | 3 | 1 |
| ProQuest | "EXPERTS BY EXPERIENCE" AND "EDUCATION" OR "ONLINE" | FULL ACCESS, FREE ACCESS, WITHIN THE LAST 10 YEARS, PEER REVIEWED | 303 | 13 | 6 | 3 |
| Finna.fi | "EXPERTS BY EXPERIENCE" AND "EDUCATION" OR "LEARNING" OR "ONLINE" | FULL ACCESS, FREE ACCESS, WITHIN THE LAST 10 YEARS | 1 | 0 | 0 | 0 |
| Google Scholar | "EXPERTS BY EXPERIENCE" AND "EDUCATION" OR "LEARNING" OR "ONLINE" | FULL ACCESS, FREE ACCESS, WITHIN THE LAST 10 YEARS | 12 | 3 | 3 | 1 |
| | "EXPERTS BY EXPERIENCE" AND "DIGITAL EXCLUSION" | | 56 | 5 | 3 | 2 |

| | | | | | | |
|--------------------|---|--|----|---|---|---|
| ScienceDirect | "EXPERTS BY EXPERIENCE" AND "EDUCATION" OR "DIGITALIZATION" | FULL ACCESS, FREE ACCESS, WITHIN THE LAST 10 YEARS | 70 | 3 | 3 | 2 |
| EBSCOhost combined | "EXPERTS BY EXPERIENCE" | FULL ACCESS, FREE ACCESS, WITHIN THE LAST 10 YEARS | 62 | 5 | 4 | 0 |

Table 1. The search process

I started with skimming through the titles on each result, and then reading the abstract on the most promising articles, which helped me to reduce the amount of results down to 30 (additional 6 though the second search). I then looked at the articles more closely, reading though 22 of them. In the end of the search process, EBSCOhost or Finna did not produce any relevant results. The second search with search words "experts by experience" AND "digital exclusion" resulted in two additional articles for the literature review, both from Google Scholar. Nine articles were finally chosen for this thesis, and they will be introduced below.

5.3 Search results

After evaluating the search results nine articles were chosen. Each had a quite different approach to experts by experience online presence. Each article will be introduced here briefly, with full details on Appendix 1.

Six articles were chosen on SAGE based on the abstract, and after reading three of them only one was chosen, article by Lindström and Rantanen (2021) titled "Experts of the streets: The thoughts of experts by experience with a history of crime and substance abuse on working as a team with professionals". This study examines the accounts of trained experts-by-experience with history of crime and substance abuse collaborating with team of professionals navigating through their dual role.

ProQuest Central database produced over 300 initial results, with the vast majority being irrelevant. Based on the abstract thirteen were chosen, and after reading this was narrowed down to three articles. The first article was titled "*PPI? That sounds like Payment Protection Insurance*": Reflections and learning from a substance use and homelessness study Experts by Experience group" by Foster, Carver, Wallace, Dunedin, BurrIDGE, Foley, Pauley and Parkes (2021). The study focuses on the importance of Patient and Public Involvement, in the field of substance abuse and homelessness.

The second article is by Palukka, Haapakorpi, Auvinen and Parviainen (2021), titled "Outlining the role of experiential expertise in professional work in health care service co-production. The article examines the role of experiential knowledge in service co-production to develop opiate substitution treatment services (OST) for high-risk opioid users".

The third article produced from ProQuest was a study titled "The Third Position" by Lees, Lomas and Haigh. The purpose of the study is to describe the benefits and challenges of the complex and fluid role of expert by experience in mental health services.

The first search on Google Scholar resulted in one suitable article from the initial 12 hits: "Expert by Experience involvement in Mental Health Nursing Education: the coproduction of standards between Experts by Experience and Academics in Mental Health Nursing" by Horgan, Manning, O'Donovan, Doody, Savage, Bradley, Dorrity, O'Sullivan, Goodwin, Greaney, Biering, Bjornsson, Bocking, Russell, MacGabhann, Griffin, van der Vaart, Kornelis, Allon, Granerud, Hals, Vatula, Ellilä, Lahti and Happell (2020). The aim of the study was to develop mental health nursing education through lived experience of service use.

The second search on Google Scholar resulted in two relevant results. The first of the two was a research by Pathway UK Healthcare for Homeless People titled "Digital health inclusion for people who have experienced homelessness - is this realistic aspiration?" with authors Dorney-Smith, Burrige, Bell, Ellis and Snowball (2017). This research studies the use of digital technology, including health care applications by people experiencing homelessness and their enthusiasm to use them in the future.

Second of the two from the additional search was an article titled "A Qualitative Study Exploring Access to Mental Health and Substance Use Support among Individuals Experiencing Homelessness during COVID-19" by Adams, Parker, Jablonski, Kennedy, Tasker, Hunter, Denham, Smiles, Muir, O'Donnell, Widnall, Dotsikas, Kaner, Ramsay (2022). The study focuses on the experiences of accessing mental health and substance abuse support for people, who are experiencing homelessness during the corona pandemic.

Finally, the data search on Science Direct produced two relevant articles. The first article titled "Leadership as Experts by Experience in Professional Education" by Curran, Sayers and Percy-Smith (2014) is set to explore and develop the experts by experience involvement in social and health care education with Knowledge Cafe approach.

The final result was a study by Stevens, Ray, Thirunavukarasu, Johnson, Jones, Miller and Elston (2021) titled "The experiences of socially vulnerable groups in England during the COVID-19 pandemic: A rapid health needs assessment". This article focuses on urgently identifying the needs of socially vulnerable marginal groups through the first wave of the Covid-19. This article also investigates the digital exclusion of the vulnerable people.

5.4 Data analysis

The articles chosen for this literature review need to be analysed. Content analysis has been chosen as a method to group and collect data on this thesis. According to Tuomi & Sarajärvi (2018) content analysis is the main method to use in qualitative research. Content analysis is used to analyse any kind of documents, including books, articles, diaries, interviews, anything that's written. Content analysis gathers the data for conclusion. (Tuomi & Sarajärvi 2018, 117). This thesis uses articles and reports as documents.

A range of research can benefit from content analysis and it can also be seen its own method as well as a loose theoretical framework that can be linked to different methods. (Tuomi & Sarajärvi 2018.) The purpose of the analysis is to create a concise description of the phenomenon being studied. (Tuomi & Sarajärvi 2018.)

According to Tuomi & Sarajärvi, there are three different analysis models, though which the analysis can be approached from. In this thesis I will be analysing the documents based on the method of Miles & Huberman (1994).

First, the original statements from the documents are simplified, or reduced so that only the relevant material remains.

| Original phrases | Simplified |
|---|---|
| <p>”Participants from across all target groups and ages reported that lack of or limited access to the internet and technology was a significant barrier to accessing official COVID-19 guidance and information, which was being published and regularly updated online. The most common reason for digital exclusion identified from the interviews was not having the resources to obtain mobile data or wireless internet.” (Stevens et al. 2021.)</p> | <p>Main reason for digital exclusion was not being able to access mobile data or wireless internet.</p> |

| | |
|--|--|
| <p>”When speaking about experiences accessing services, individuals reflected on the pre-pandemic in-person support with general positivity although recognising it was not without its faults.” (Adams et al. 2022.)</p> | <p>In-person support was deemed as a positive thing, yet with some issues.</p> |
|--|--|

Table 2. An example of simplifying

Step two in the process sees simplified expressions divided into groups, or clusters. Similar or connecting expressions are gathered into subcategories, which are then named after the context of the data. Subcategories are then connected to form upper categories and upper categories are connected to form main categories (Tuomi & Sarajärvi 2018, 122-127).

| Simplified | Clustering | Subcategorized |
|--|--|---|
| <p>Main reason for digital exclusion was not being able to access mobile data or wireless internet.</p> <p>In-person support was deemed as a positive thing, yet with some issues.</p> | <p>Access to internet</p> <p>Access to a device</p> <p>Lack of experience with digital tools</p> <p>Effectiveness of in-person support</p> | <p>Inclusion</p> <p>Availability</p> <p>Digital exclusion</p> <p>Lack of experience</p> |
| <p>Bespoke training with online applications is required.</p> <p>Experts by experience must be empowered and given an opportunity to grow as professionals.</p> | <p>Training solutions</p> <p>Digital training skills</p> <p>Professional support</p> <p>Encouraging</p> <p>Giving feedback</p> | <p>Training</p> <p>Support</p> <p>Empowerment</p> <p>Reflection</p> |

| | | |
|---|------------|--|
| Feedback and debriefing are essential. | Debriefing | |
|---|------------|--|

Table 3. An example of clustering and subcategorizing

Connecting expressions this way seeks to answer the research questions set (Tuomi & Sa-
rajärvi 2018, 127).

| Subcategories | Connective categories |
|--|--|
| Inclusion Availability Digital exclusion Lack of experience | Experts by experience online education and other activities online |
| Training Support Empowerment Reflection | Factors for promoting inclusion for experts by experience |

Table 4. An example of connective categorizing

5.5 Ethical consideration and reliability

Good ethical practice is the foundation for ethically acceptable research. Research follows the guidelines set by the scientific community; honesty, general care, precision, and attention to detail. Acquisition of information, research and evaluation methods must comply with scientific research criteria and be ethically sustainable. Good scientific practice also includes transparency in research results when published. Researcher also need to consider the work and achievements of other researchers in a manner that respects their work and give them the credit due. Sources of funding or other conflicting interests should be to participants in the study. (TENK 2012).

It is important for the reliability of the research to record the subject of the research and its purpose on the researcher's own opinion. In addition, it is important to document the method, technique, the potential problems. The research schedule, the info on how the material was analysed and how conclusion was reached, as well as evaluation and reporting of the findings must be recorded. (Tuomi & Sarajärvi 2018, 163-164).

In my thesis I have attempted to document all the steps of my research as precisely as possible. The data searches have been noted down. I was working alone and there are no financial ties to any direction. I am using other researchers' articles as the material to be studied, and all of them have been properly credited. My thesis was conducted as a descriptive literature review. This type of review allows the researcher more freedom as there are no exact rules and the research questions can be looser than in other types of literature review (Salminen 2011). The viewpoints stated in the conclusions are my own. I documented all my findings clearly. All the articles in my research were published in English. My native tongue is Finnish but consider my English skills to be on a high level. However, working on my second language leaves a possibility of misinterpretation.

6 Findings

This chapter focuses on the key findings from the articles regarding the research questions. The articles did not provide exact answers to the set questions but will be gathering existing research around the subject. The first section will be introducing findings on experts by experiences' online presence and learning experiences. The second part focuses on how to better include experts by experience in the digitalization. Discussion on the findings can be found in section 6.3.

6.1 Experts by experience online presence and learning experiences

Experts by experience involved in the Mental Health nursing education are lacking structure and support. These factors often result in inadequate preparation and debriefing and involvement as a "token." It was identified that experts by experience need to feel empowered and have the confidence to become involved in higher education. Experts by experience also need emotional and practical preparation to act as an educator. (Horgan et al. 2020). When collaborating with a team of professionals, experts by experience found themselves being experts of the lived experience, whereas they saw that the strengths of the professionals were the skills that were acquired through education. (Lindström & Rantanen 2021).

Research by Dorney-Smith et al. (2017) found that people experiencing homelessness and identifying as experts by experience had several issues accessing health applications online. There was a considerable amount of pre-existing internet use, but still a third did not use the internet at all and had 'below average' or 'poor' internet skills. Issues among the people experiencing homelessness included lack of appropriate device, data availability and inadequate access to wi-fi. Reading and writing were also an issue, when filling online forms in example. The study found that there was a willingness and enthusiasm for further use of the internet, including health apps.

A study exploring Mental Health and Substance Abuse support among the homelessness during COVID-19 saw Experts by Experience become a part of the core project team and assist in the design of the study and understanding of interviews. Findings state that there was inadvertent exclusion due to the rapid and reactive changes in service provision due to COVID-19. The change to remote services suited some participants but left many feeling excluded. There were unspoken expectations from professional in accessing support digitally. There were also limitations in finding out about the support that was available due to the lack of access to internet, as well as lacking skills (Adams et al. 2022).

A study by Stevens et al. (2021) found that the participants from vulnerable groups, half of whom were experts by experience had challenges accessing and following COVID-19 information and government guidance due to digital exclusion. Online patient registration and access to healthcare were also mentioned as an issue. For these experts by experience the most common reason for digital exclusion was not having mobile data or access to wi-fi. Once the support groups closed due to the pandemic, the socially vulnerable people lost their access to data.

6.2 Furthering experts by experiences' online learning and promoting inclusion

A study by Horgan et al. (2021) sees that attempts have been made to address the lack of training amongst experts by experience in nursing education. Experts by experience must be

well-prepared, trained, given opportunities to reflect and debrief and offered any support they need to present their material within the nursing education. Experts by experience may need to take part in additional training, such as IT skills and Virtual Learning Environments.

The research examining people experiencing homelessness highlighted some improvements, which might help more experts by experience online. These included improved access to internet, basic training and skills development. Two-thirds of the respondents said they would be interested in taking part on a pilot programme to help people experiencing homelessness to access the internet more (Dorney-Smith et al. 2017).

COVID-19 presented an opportunity to gain experience from the rapid changes in services in mental health care and substance abuse support for people experiencing homelessness. (Adams et al. 2022). Another research on vulnerable groups during COVID-19 finds that digital exclusion must be addressed to facilitate access to information and services, including free data or access to wi-fi for socially vulnerable groups (Stevens et al. 2021).

6.3 Discussion on findings

Based on the research, I could not find exact answers to my research questions, but gained knowledge around them. There are many meanings for 'experts by experience' in these studies. Some researchers refer to experts by experience as someone who is living or has living experience, whereas some describe expert by experience as someone, who has been through a training program. There was no direct reference to experts by experience online learning experiences either, which had me broaden my research question to include online presence, activities, skills, and learning. I was able to extract results around the research questions regardless.

The results showed that in general, experts by experience lacked either training, skills, knowledge, or guidance on their online activities. Especially the people, who were socially vulnerable could not access the internet due to device or data issues. There were issues overall with lacking confidence collaborating with professionals and the need for empowerment. COVID-19 had a drastic impact on people already in a bad position socioeconomically.

Many improvements are also being implemented to increase inclusion for experts by experience. There are demands for further training for experts by experience as well as plans for low threshold access to internet services and a push to help experts by experience to gain access to higher education. More inclusion and involvement for experts by experience is need for them to carry on the work with peer support and educating.

7 Conclusions

As this chapter concludes my thesis, I can finally look back at my study process and highlight what I have learned. It has been a long journey with mixed emotions. The following will open up the process and my final thoughts.

This process started in fall 2021. I was attending my final courses and planning to do my thesis as a functional one. The plans just never came a reality, and I was deflated. There was an email about the Experts by Experience online project and the need for a literature review for the project. I have always considered myself more practical than theoretical and had never thought of literature review as a method. The subject sparked my interest, and I decided to think outside the box; structure and rules was exactly what I needed to complete my studies.

During the process of doing my thesis, I have spent a lot more time worrying about the work that has not been completed than doing the work. I have found myself underestimating the time each part of the process takes and have been overwhelmed by the sheer amount of material and ideas. I have gained more understanding on literature review and doing research in general.

I have learned a great amount of self-discipline and not to be ashamed of my own writing. I have tried to also learn to balance the workload but accepted that some things cannot be rushed. I am pleased that this process is coming to an end, at times it felt like it was not going to be completed due to working alone.

I could have gone so many ways with my research as there would be so many interesting research subjects even within experts by experience and online learning. However, the next time I am doing research will be conducting it full time, not while studying and working.

There is a need for experts by experience in social and health care, but they need to be provided with proper training, in classroom and online, empower them and provide them with equal opportunities and the right tools in the changing environment. It is going to be a lot of work, but preventive measures will help to develop the experts by experience role further.

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Appendices

Virhe. Kirjanmerkkiä ei ole määritetty.

Appendix 1. The data matrix

| Database | Research and authors | The aim of the research | Method / analysis | Relevant findings |
|----------------|---|---|--|--|
| Google Scholar | Horgan, A. et al. 2020. Expert by Experience involvement in Mental Health Nursing Education: the co-production of standards between Experts by Experience and Academics in Mental Health Nursing. | To develop standards for expert by experience involvement in mental health nursing training based on user experience. | Qualitative descriptive methods, involving focus groups with service users | Support and structure for expert by experience involvement is lacking, as a result preparation can be inadequate. Standards are designed to provide better structure to support experts by experience in higher education. |
| Google Scholar | Dorney-Smith, S.; Burrige, S.; Bell J.; Ellis, J.; Snowball, L. 2017. Digital health inclusion for people who have experienced homelessness - is this realistic aspiration? | To examine the potential for people, who are experiencing homelessness to use and engage with digital health apps. | Surveys, focus groups and a literature review. | There is some current use of digital health apps as well as an interest for further use. There are issues with capability and access, which are ongoing. The report makes recommendations to address the issues. |

| | | | | |
|-----------------------|---|--|--|---|
| Google Scholar | <p>Adams, E.A.; Parker, J.; Jablonski, T.; Kennedy, J.; Tasker, F.; Hunter, D.; Denham, K.; Smiles, C.; Muir, C.; O'Donnell, A.; et al. 2022.</p> <p>A Qualitative Study Exploring Access to Mental Health and Substance Use Support among Individuals Experiencing Homelessness during COVID-19.</p> | <p>To study the access to community based mental health and substance abuse support for people experiencing homelessness during the COVID-19 pandemic.</p> | <p>Qualitative telephone interviews. Inductive reflective thematic analysis.</p> | <p>There is a need for accessible and bespoke support for people experiencing homelessness.</p> |
| ScienceDirect | <p>Curran, T.; Sayers, R.; Percy-Smith, B. 2014. Leadership as Experts by Experience in Professional Education.</p> | <p>To explore and develop leadership involved in social and health care education and research by experts by experience.</p> | <p>A Knowledge Cafe method.</p> | <p>Past experiences as a service user drove experts by experience to challenge and change the health care services.</p> |
| ScienceDirect | <p>Stevens, A. J.; Ray, A.M.; Thirunavukarasu, A.;</p> | <p>To urgently identify the needs of groups of people, who</p> | <p>Needs assessment. Thematic analysis.</p> | <p>The study found challenges in accessing COVID-19</p> |

| | | | | |
|-----------------|--|---|--|---|
| | Johnson, E.; Jones, L.; Miller, A.; Elston, J. W.T. 2021. The experiences of socially vulnerable groups in England during the COVID-19 pandemic: A rapid health needs assessment. | are socially in a vulnerable position, based on the first wave of cases of the COVID-19 pandemic. | | information and guidance due to exclusion from digital technologies, housing issues, and the general lack of translated resources and tailored support. |
| SAGE | Lindström, J.; Rantanen, T. 2021. Experts of the streets: The thoughts of experts by experience with a history of crime and substance abuse on working as a team with professionals. | To explore the reflections from experts by experience, who have undergone a training as they find their place working with a team of professionals. | Themed interviews. Narrative. | Experts by experience see themselves and are seen as both an interpreter and an advocate trying to build understanding between the customer and the professional. |
| ProQuest | Foster, R.; Carver, H.; Wallace, J.; Dunedin, A.; Burridge, S.; Foley, P.; Pauly, B.; Parkes, T. 2021. "PPI? That sounds like Payment Protection Insurance": | To share experiences on being a part of Patient and Public Involvement group. | The Supporting Harm Reduction through Peer Support (SHARPS) study. | It is essential that people with substance abuse issues and homelessness experiences have chances to contribute to research in a |

| | | | | |
|-----------------|--|---|---|---|
| | Reflections and learning from a substance use and homelessness study Experts by Experience group. | | | meaningful way. |
| ProQuest | Palukka, H.; Haapakorpi, A.; Auvinen, P.; Parviainen, J. 2021. Outlining the role of experiential expertise in professional work in health care service co-production. | To examine the role of expert by experience in service co-production in order to develop opiate substitution treatment for high-risk users. | Meetings. Content analysis, discourse analysis. | The meetings fail to provide any new ideas for fixing the problems, despite the opportunity for creativity and problem-solving. |
| ProQuest | Lees, J.; Lomas, F.; Haigh, R. 2019. The Third Position. | To explore the role, benefits and challenges of experts by experience. | Literature review, case study. | The role of expert by experience is complex and fluid. |