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OUTCOMES OF EXPERTS BY EXPERIENCE IN (MENTAL) HEALTH CARE AND SOCIAL DOMAIN: A SCOPING REVIEW

IMPACT VAN ERVARINGSDESKUNDIGEN IN (MENTALE) GEZONDHEIDSZORG EN HET SOCIALE DOMEIN: EEN SCOPING REVIEW

NICOLE VAN ERP, SIMONA KARBOUNIARIS, SASKIA KEUZENKAMP, ROSALIE METZE, RENSKE VAN DER ZWET

ABSTRACT

Peer support and peer-supported services have expanded broadly in Western countries. In the Netherlands there is a tendency, especially in mental health care, to further professionalize peer support. As a result, there is growing interest in the outcomes of experts by experience regarding participants who receive their support.

This article reports on a scoping review that aimed to identify and synthesize qualitative research into the outcomes of experts by experience working in (mental) healthcare services and organizations in the social domain. We synthesized the findings of 32 studies. The outcomes were organized into three clusters: psycho-social outcomes, life domain outcomes and treatment outcomes.

Psychosocial outcomes are most frequently mentioned. In all articles included, one or more psychosocial outcomes were found, e.g. reduced feelings of loneliness and isolation, more hope for a better life and increased self-confidence. More than half of the articles report positive outcomes in life domains, especially outcomes on family relations, social contacts and community engagement. Outcomes in terms of symptoms and treatment improvements were mentioned in about one-third of the included articles, such as symptom relief and shorter admissions.

To get a clearer picture of the mechanisms that lead to the outcomes, more specific information is needed about what experts by experience do in their 'experience work'.

KEYWORDS

Peer support, experts by experience, outcomes, (mental) health care, social domain

SAMENVATTING

De inzet van ervaringsdeskundigheid heeft zich in westerse landen breed verspreid. In Nederland is er, vooral in de geestelijke gezondheidszorg, een tendens om ervaringsdeskundigheid verder te professionaliseren. Als gevolg hiervan is groeiende belangstelling voor de impact van de inzet van ervaringsdeskundigheid op deelnemers die ondersteuning ontvangen.

Dit artikel doet verslag van een scoping review die tot doel had kwalitatief onderzoek naar de uitkomsten van de inzet van ervaringsdeskundigheid in de (geestelijke) gezondheidszorg

en het sociale domein te identificeren en synthetiseren. In de review zijn de resultaten van 32 studies samengevat in drie clusters: psychosociale uitkomsten, uitkomsten op het gebied van levensdomeinen en behandeluitkomsten.

Psychosociale uitkomsten komen het vaakst naar voren. In alle geïncludeerde artikelen werden één of meer psychosociale uitkomsten gevonden, zoals minder gevoelens van eenzaamheid en isolement, meer hoop op een beter leven en meer zelfvertrouwen. Meer dan de helft van de artikelen rapporteert positieve resultaten op levensdomeinen, zoals familierelaties en sociale contacten en maatschappelijke betrokkenheid. Resultaten in termen van symptoomvermindering en verbeteringen van de behandeling werden genoemd in ongeveer een derde van de geïncludeerde artikelen.

Om een duidelijker beeld te krijgen van de mechanismen die tot de uitkomsten leiden, is meer specifieke informatie nodig over wat ervaringsdeskundigen doen in hun 'ervaringswerk'.

TREFWOORDEN

Peer support, ervaringsdeskundigheid, resultaten, (geestelijke) gezondheidszorg, sociaal domein

INTRODUCTION

Peer support and peer-supported services have experienced significant growth since their introduction a few decades ago, particularly in Western countries. Initially rooted in mental health care, peer support has now expanded into other areas, including somatic care, youth programs, and the broader social domain. This expansion has led to a more widespread recognition of the value of lived experience, increased accessibility to support services, and the integration of peer support into formal healthcare structures.

According to an updated definition by Fortuna et al. (2022, p. 573), peer support involves "social and/or emotional support that combines expertise from lived experience, delivered with mutual agreement by individuals who self-identify as having or having had mental health as well as other social, psychological, and medical challenges, to service users with similar challenges, aiming to foster self-determined personal change". Peer support can take various forms, such as one-to-one interactions, group sessions, and online or telephone support. It may be provided informally by peers

or more formally by trained experts by experience (Fortuna et al., 2022; Grant et al., 2021). Beyond individual support, peer support workers contribute to policy development, education, research, and advocacy. These individuals are often referred to as peer providers, peer support specialists, peer mentors, or experts by experience; this article primarily uses the term experts by experience.

Rooted in the recovery movement, experts by experience are part of a larger transformation of services. Recovery-oriented work by experts by experience involves fostering a culture that supports the individual's recovery process, provides hope, encouragement, and practical strategies to help service users to discover and achieve their personal goals and values. This approach underscores the importance of mutual learning, respect, and the shared understanding of recovery as a unique and personal process. The recovery movement has already achieved significant milestones, including the shift from a purely medical model to a more holistic, person-centred approach that values lived experience and promotes empowerment, hope, and self-determination (Repper & Perkins, 2003).

In the Netherlands, there is an increasing trend, especially in mental health care, towards the professionalization of peer support (Weerman, 2016). This has spurred interest in evaluating the outcomes of services provided by experts by experience. Knowledge about the impact is relevant for experts by experience and service users, but also for other professionals, policy makers and health insurance companies. Recent literature includes several reviews and meta-analyses. For instance, a synthesis of reviews on the impact of experts by experience in one-on-one interactions within the social domain found inconclusive results (Keuzekamp & Van Hoorn, 2022). Smit et al. (2023) found that peer support interventions had modest effects on clinical recovery– focusing on symptom reduction and improved mental health- and personal recovery- focusing on attaining a meaningful and fulfilling life- outcomes, though not on functional recovery- focusing on the restoration of daily functioning and participation in society. The most recent (systematic umbrella) review we found, summarized studies on the effectiveness of paid peer support approaches for mental health (Cooper et al., 2024). The results were mixed; there was some evidence that peer support may improve depression symptoms, self-efficacy, and recovery.

These reviews predominantly feature quantitative studies. This scoping review seeks to identify and synthesize qualitative studies to provide a richer and more comprehensive understanding of the impact of experts by experience. Quantitative methods are not always the most effective way to capture the complexity of interventions and daily life challenges in the social domain

(Omlo et al., 2013). This review aims to complement the previous predominantly quantitative reviews by exploring the qualitative evidence available.

The current research question guiding this scoping review is: "What are the qualitative outcomes of experts by experience working in (mental) healthcare services and organizations in the social domain?" This question aims to thoroughly explore the lived experiences and perceived impacts of peer support from the perspective of the service users. By focusing on qualitative outcomes, this research seeks to capture the nuanced, subjective experiences that quantitative methods may overlook. This includes understanding the personal transformations of service users, the relational dynamics and working mechanisms within peer support interactions, and the broader implications for service delivery and policy development in health and social care sectors.

METHODS

The proposed scoping review was conducted following the JBI methodology for scoping reviews (Tricco et al., 2018).

Search strategy

We searched the following databases: PsycINFO, PubMed, Web of Science, Cochrane Library and CINAHL from 2012 up to the 22nd of June 2022. The literature search was conducted by five researchers, supported by a data steward. The research question led to further operationalization and a refined search string combining the following terms: (("peer support worker" OR "PSW" OR "lived experienced practitioner" OR "LEP" OR "expert by experience" OR "ExE" OR "therapatient" OR "experiential expert" OR "peer specialist" OR "wounded healer" OR "user expert" OR "user survivor" OR "peer support" OR "peer-delivered" OR "peer service" OR "consumer-run" OR "consumer leaders" OR "consumer-operated" OR "consumer providers" OR "mutual help group" OR "Photovoice") AND ("effect" OR "outcomes" OR "evidence" OR "efficacy" OR "effectiveness" OR "impact" OR "value")) and a broad range of contexts in the following MeSH terms: mental health, community health, addiction/substance abuse, youth, poverty, revalidation, discrimination, diversity, handicap, gender diversity, women's shelter, sexual violence.

A preliminary check with three different search strings resulted in 16.599 publications and after deduplication 8.437 publications.

Screening of papers

A set of inclusion and exclusion criteria was used to ensure the publications selected captured the research question. Papers were included if they: (1) were qualitative studies; (2) reported on the outcomes of experts by experience working in (mental) health care services and social organizations to service users/participants receiving their support; (3) were conducted in western countries; (4) were peer-reviewed. The articles had to be available online, and identifiable through an electronic database.

We screened titles and abstracts to identify eligible papers for inclusion. We worked intersubjectively and discussed concerns and doubts. Articles from meta-reviews were excluded, as well as publications focusing on peer support or advocacy in research or education/ training settings. This resulted in 62 eligible papers for inclusion. In a second round of screening, we examined full texts of the 62 papers to determine final inclusions. We only included peer-to-peer support, self-help groups and similar interventions if facilitated by an expert by experience. After this second round of screening 32 articles were included in the scoping review (see Figure 1). These remaining articles concerned research and empirical findings, critical interpretive reviews, evaluation and narrative reviews.

Data extraction

Data from selected studies were extracted using a standardized data collection form amended for this review. This tool captured information related to the characteristics of studies, including study setting, whether the expert by experience was trained/ educated, whether the expert by experience was paid, one-to-one or group support, the nature of the support, a description of outcome(s) and method(s) of evaluation.

Quality assessment

The quality of the 32 selected publications was assessed using the CASP Qualitative checklist (Checklist, 2018). This checklist consists of 10 questions and is designed to assess the study's methodological rigour, validity, and relevance (see Table 1).

In 6 out of 32 studies, all 10 questions were appraised positively. In 15 out of 32 studies, 1 question was appraised negatively. In 6 out of the 32 studies, 2 questions were appraised

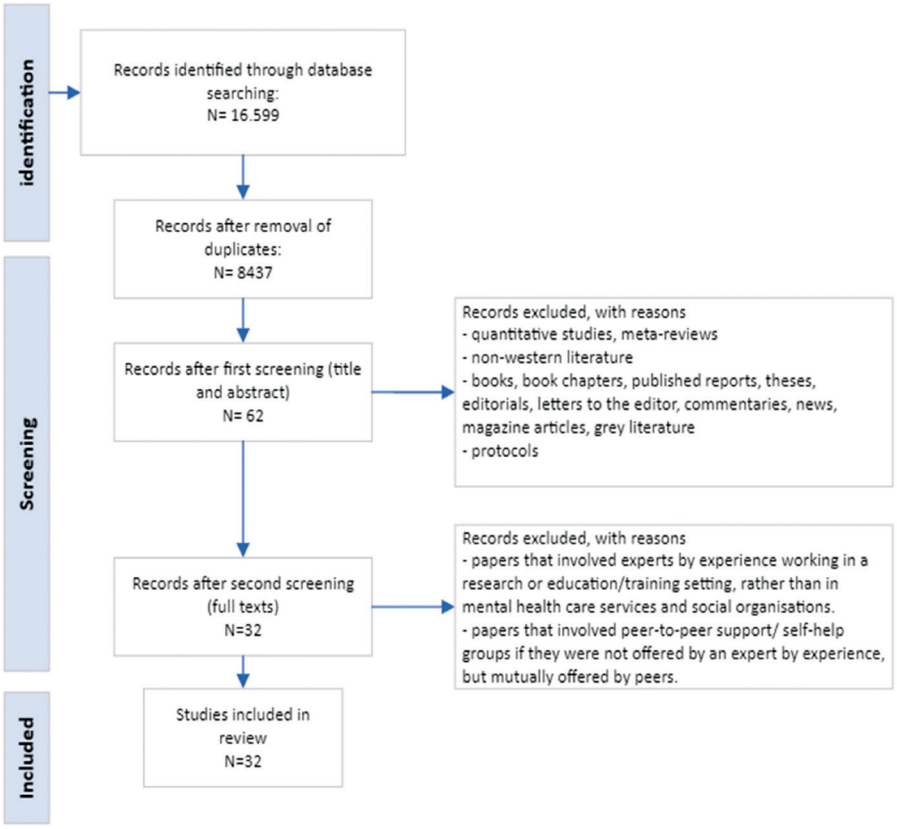

Figure 1: Flow chart.

negatively. In 5 out of the 32 studies, 3 or more questions were appraised negatively. Furthermore, in about 10% of the questions we were not able to assess the study, because of the lack of information provided. Overall, the included studies are of modest quality.

RESULTS

In this section, we first describe the context within and the role in which the experts by experience were active. Then we present the outcomes of the support by experts by experience

Table 1: Results of the CASP qualitative checklist.

Question	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?	32	0	0
2. Is a qualitative methodology appropriate?	31	1	0
3. Was the research design appropriate to address the aims of the research?	28	4	0
4. Was the recruitment strategy appropriate to the aims of the research?	26	4	2
5. Was the data collected in a way that addressed the research issue?	28	4	0
6. Has the relationship between researcher and participants been adequately considered?	13	11	8
7. Have ethical issues been taken into consideration?	26	5	1
8. Was the data analysis sufficiently rigorous?	27	5	0
9. Is there a clear statement of findings?	28	3	1
10. How valuable is the research?	29	0	3

for participants who receive their support. Elaborating on Keuzekamp & Van Hoorn (2022), all outcomes found in the selected studies were organized into three clusters: psycho-social outcomes, life domain outcomes and treatment outcomes.

Description of interventions and role of the expert by experience

In line with the aforementioned expansion of peer supported services from mental health care to other domains, there are various contexts within which, and circumstances under which, experts by experience in the included studies work. Starting with the context, 22 of the 32 articles reported on research in the context of mental health care, sometimes combined with addiction, youth care, homelessness and veteran services. Other contexts included maternal care, somatic care, the social domain, community care and forensic services.

The interventions carried out by the experts by experience were in 17 articles embedded within regular care contexts. For example, experts by experience were incorporated in regular perinatal opioid use disorder treatment, or it was a separate activity within a prevention and early intervention program for psychosis. In 13 articles, the interventions of the experts by experience

were stand-alone, meaning they were separate interventions not incorporated within regular care organizations. For example, an article reported on 'dual diagnosis anonymous' as a peer-led program, and another article focused on a non-profit organization providing peer-delivered services. In 2 articles it was a mix of both.

Most of the interventions were individual, as we found in 14 articles. This could entail face-to-face or telephone meetings or therapy sessions. In 5 articles, collective interventions were researched, for example recovery groups or educational sessions. In 10 cases it was a combination of both and in 3 articles, it was unclear what kind of interventions the experts by experience carried out.

In 14 studies the experts by experience were employed and had a paid position. In 6 studies, they worked as volunteers, and in 5 studies it was a mix between paid and voluntary work. In 7 articles, it was not specified whether experts by experience had a paid or voluntary position.

When it comes to training of the experts by experience, 21 of the articles mentioned some sort of training, although the content differs greatly. Some training programs focused specifically on competencies for experts by experience, such as principles and values underpinning recovery and peer support, or a strength-based approach (strength-based approaches focus on individuals' strengths, such as personal strengths and social and community networks, and not on their deficits). Other programs were more focused on knowledge necessary within the specific care context. However, in many articles the content of the training program was not specified. In 3 articles, it was clear that no training program was followed, and in 8 articles there was no mention of training.

In addition to the heterogeneity of contexts and circumstances, we noticed that in many of the articles the activities experts by experience carry out are not clearly described. As a result, it is difficult to get a clear idea of the role of the experts by experience.

Psychosocial outcomes

All of the 32 included studies reported on psychosocial outcomes (see Table 2). We found many different terms concerning psychosocial outcomes. In our review, we created three clusters. The first we called 'state of mind', how do participants feel as a consequence of having participated in the project? The second cluster concerns how they evaluate themselves, and their self-appreciation. The third cluster concerns outcomes related to the interaction with others, especially with the experts by experience.

Table 2: Psychosocial outcomes.

State of mind	
Less alone, less isolated	Balogun-Mwangi et al. (2017), Gidugu et al. (2015), Greenwood et al. (2013), Gregory et al. (2022), Hancock et al. (2022), Hock et al. (2022), Kessler et al. (2014), King & Simmons (2023), Levasseur et al. (2019), McCarthy et al. (2019), Sattoe et al. (2013), Theurer et al. (2021), Visa & Harvey (2019)
Hopeful	Balogun-Mwangi et al. (2017), Barr et al. (2022), Cust (2016), Fitch et al. (2017), Gidugu et al. (2015), Greenwood et al. (2013), Gregory et al. (2022), Hopkins et al. (2021), King & Simmons (2023), Kumar et al. (2019), Milani et al. (2020), Smith et al. (2020), Taylor et al. (2018), Prat Vigué et al. (2022)
Motivated	Gigugu et al. (2015), Henderson & Kemp (2013) Ingram (2013), Ingram et al. (2020), Kessler et al. (2014), Thomson & Crossland (2019)
Focus on better life and future	Balogun-Mwangi et al. (2017), Barr et al. (2022), Gidugu et al. (2015), Hancock et al. (2022), Milani et al. (2020), Schel et al. (2022), Prat Vigué et al. (2022)
Stress	Fitch et al. (2017), Gidugu et al. (2015), Gopalan et al. (2017), Kumar et al. (2019), Smith et al. (2020), Thomson & Crossland (2019)
Personal growth	Gregory et al. (2022), Schel et al. (2022)
Self-appreciation	
Self-confidence	Balogun-Mwangi et al. (2017), Gidugu et al. (2015), Gregory et al. (2022), Henderson & Kemp (2013), Ingram (2013), Levasseur et al. (2019), Milani et al. (2020), Sattoe et al. (2013), Smith et al. (2020), Taylor et al. (2018)
Self-esteem	Cust (2016), Gidugu et al. (2015), Greenwood et al. (2013), Levasseur et al. (2019), Milani et al. (2020), Schel et al. (2022)
Self-efficacy	Ingram et al. (2020), Milani et al. (2020), Sattoe et al. (2013)
Self-stigma	King & Simmons (2023), Milani et al. (2020), Weir et al. (2019)
Positive identity, feeling useful	Cust (2016), Gidugu et al. (2015), Henderson & Kemp (2013), Milani et al. (2020), Prat Vigué et al. (2022)

Table 2: Continued

State of mind	
Empowered	Gregory et al. (2022), Prat Vigué et al. (2022)
Coping better	Fitch et al. (2017), Gidugu et al. (2015), Greenwood et al. (2013), Gregory et al. (2022), Hancock et al. (2022), Henderson & Kemp (2013), King & Simmons (2023), Kumar et al. (2019), Milani et al. (2020), Schel et al. (2022), Shiyanbola et al. (2022), Smith et al. (2020), Visa & Harvey (2019)
Interplay with others	
Feeling understood, heard	Barr et al. (2022), Fitch et al. (2017), Gregory et al. (2022), Hancock et al. (2022), Hopkins et al. (2021), Levasseur et al. (2019), McCarthy et al. (2019), Schel et al. (2022), Thomson & Crossland (2019), Prat Vigué et al. (2022), Weir et al. (2019), Wroblenski et al. (2015)
Feeling accepted and respected, not judged	Barr et al. (2022), Fitch et al. (2017), Gidugu et al. (2015), Milani et al. (2020), Visa & Harvey (2019)
Feeling emotionally supported	Fallin-Bennet et al. (2020), Fitch et al. (2017), Gidugu et al. (2015), Gregory et al. (2022), Visa & Harvey (2019)
Normalized, reassured	Cust (2016), Gidugu et al. (2015), Greenwood et al. (2013), Hock et al. (2022), Ingram et al. (2020), Weir et al. (2019)
More open to others, more prosocial	Gregory et al. (2022), Milani et al. (2020), Sattoe et al. (2013), Theurer et al. (2021)

State of mind

The majority of studies (28 out of 32) reported positive outcomes about what participants said about their state of mind. In many of them, participants said they feel less alone in their experiences, struggles and despair (e.g. Balogun-Mwangi et al., 2017; Gidugu et al., 2015; Greenwood et al., 2013). They felt less isolated. Also, more hope is often reported (e.g. Hancock et al., 2022; Milani et al., 2020; Smith et al., 2020). Hope for a better future, to be better able to live a satisfying life, seeing light at the end of the tunnel. In 6 studies it was mentioned that

participants got more motivated, for example, to change their way of living (e.g. Gidugu et al., 2015; Henderson & Kemp (2013). In 7 studies participants said they get more focus on a better life and future (e.g. Schel et al., 2022). Five studies mentioned participants experienced less stress (e.g. Fitch et al., 2017; Gopalan et al., 2017) and 2 reported a feeling of personal growth (e.g. Gregory et al., 2022).

Self-evaluation and self-appreciation

In 22 out of 32 studies, it was mentioned that participants thought more positively about themselves and were more capable of dealing with their issues. They had more self-confidence and their self-esteem had increased (e.g. Gidugu et al., 2015; Sattoe et al., 2013). Their belief in their own capacity to act in ways necessary to reach what they aim for (self-efficacy) had increased (e.g. Ingram et al., 2020; Milani et al., 2020). These participants felt more in control. Three studies reported a reduction of self-stigma (e.g. King & Simmons, 2023). Five studies showed that participants regained a positive identity and felt useful (e.g. Cust, 2016; Milani et al., 2020) and 2 reported the intervention had empowered the participants (Gregory et al., 2022; Prat Vigué et al., 2022). Eleven studies mentioned that participants were more capable of coping with their issues than before. Hearing other experiences and other perspectives stimulated them to try out and develop other coping strategies (e.g. Greenwood et al., 2013; Kumar et al., 2019; Visa & Harvey, 2019).

Interplay with others

22 out of 32 studies reported outcomes on how participants experience their relationships and interact with others. Participants often said they felt understood (Barr et al., 2022), accepted and not judged (e.g. Fitch et al., 2017; Visa & Harvey, 2019), and emotionally supported (e.g. Fallin-Bennett et al., 2020). The experts by experience gave participants the feeling that they were not losers. In 6 studies participants gained a sense of normality (e.g. Cust, 2016; Hock et al., 2022). Also, participants opened up to others and became more pro-social (e.g. Gregory et al., 2022; Theurer et al., 2021).

Outcomes on life-domains

18 out of 32 articles reported outcomes on life domains, which includes family relations and social contacts, community engagement, family and children, education and employment, housework/ daily routines and self-care, finances and physical health (see Table 3).

Table 3: Outcomes on life-domains.

Family relations and social contacts	
Family relations	Gopalan et al. (2017)
Couple relationship	Hock et al. (2022)
Social contact/connection/interaction	Gregory et al. (2022), Henderson & Kemp (2013), Milani et al. (2020), Shiyanbola et al. (2022), Weir et al. (2019),
Social network/relationship	Gopalan et al. (2017), Levasseur et al. (2019), Theurer et al. (2021), Weir et al. (2019)
Community engagement	
Community connection	Hancock et al. (2022), Theurer et al. (2021)
Service navigation / connection to services	Hock et al. (2022), Weir et al. (2019), Taylor et al. (2018)
Engagement community (services)	McCarthy et al. (2019), Theurer et al. (2021)
Participation in social/recreational activities	Gidugu et al. (2015)
Raising children	
Parenting role	Cust (2016), Gopalan et al. (2017)
Preparation for childbirth	Fallin-Bennett et al. (2020)
Contact with children	Hock et al. (2022)
Employment and education	
Academic involvement	Gopalan et al. (2017)
Employment	Balogun-Mwangi et al. (2017), Hancock et al. (2022)
Looking for a job, starting an internship	Schel et al. (2022)
Housework/daily routines and self-care	
Daily routines	Hancock et al. (2022)
Lifestyle	Henderson & Kemp (2013)
Self-care	Hock et al. (2022), Levasseur et al. (2019)
Finances/debts	
Finances/debts	Schel et al. (2022)

Family relations and social contacts

Ten studies described positive outcomes on family relationships and social contacts. One study mentioned participants benefited from peer support in terms of improved family communication and dynamics, and reduced family stress and conflict (Gopalan et al., 2017). In another study, participants indicated that peer support improved their co-parenting and couple relationships. The support helped them to engage in problem-solving related to parenting challenges (Hock et al., 2022). Also, participants benefited from their involvement with peers by expanding social networks and social involvement (Gopalan et al., 2017). In a study on peer support of siblings, participants described a sense of closeness and appreciation regarding connecting with peers who understood what they were going through. They stated that this contributed to a sense of belonging, acceptance and recognition that they were not alone (Gregory et al., 2022). Also, peer support led to increased social interaction and new friendships (Henderson & Kemp, 2013), restored trust and relationships with loved ones (Levasseur et al., 2019), improved social interactions with relatives and friends (Milani et al., 2020), enhanced social connections (Shiyanbola et al., 2022; Weir et al., 2019), and increased social relations (Prat Vigué et al., 2022; Theurer et al., 2021).

Community engagement

Seven studies reported outcomes on community engagement. Participants indicated that peer support helped them to participate in recreational activities (Gidugu et al., 2015), engage in community services and support (Hancock et al., 2022; Hock et al., 2022; Taylor et al., 2018, Weir et al., 2019), feel part of the community (McCarthy et al., 2019), and develop an interest in what's going on in their community (Theurer et al., 2021). The engagement enhanced their feelings of safety and social inclusion.

Raising children

Four studies described outcomes on parenting roles and raising children. In a study by Cust (2016) contact with the expert by experience increased the self-esteem of the participants towards their parenting role, and their ability to be 'a good mother'. In another study, participants reported feeling well-prepared for their delivery, due to peer support (Fallin-Bennett et al., 2020). Peer support also led to better parenting roles and skills (Gopalan et al., 2017) and a better understanding of their child's experience and new ways of interacting with them (Hock et al., 2022).

Employment and education

Four studies mentioned vocational or educational outcomes. In one study experts by experience were effective in encouraging persons to keep working towards their vocational goals (Balogun-Mwangi et al., 2017). Also, employment was part of re-establishing a meaningful routine for participants, and they described how their expert by experience facilitated this (Hancock et al., 2022). Peer support also brought participants to start looking for a job or internship (Schel et al., 2022), or improve their academic performance (Gopalan et al., 2017).

Housework/daily routines and self-care

Four studies reported outcomes in the field of housework/daily routines and self-care. In a study by Hancock et al. (2022) participants talked about the impact of peer support on their ability to return to daily life routines after leaving hospital. Also, the support of the expert by experience brought people to start making difficult lifestyle changes and maintain the gains (Henderson & Kemp, 2013). A study on peer support of caregivers mentioned that peer support allowed participants to acknowledge the need for self-care, e.g. by earmarking personal time (Levasseur et al., 2019). In a study by Hock et al. (2022) participants reported increasing their use of other strategies such as walking, listening to music, or taking a bath.

Finances

Finally, one study mentioned outcomes on the finances of participants. Support from experts by experience stimulated participants to follow a financial care trajectory (Schel et al., 2022). In other articles no outcomes on this domain were mentioned.

Outcomes in terms of symptoms and treatment improvement

Eleven of the 32 included studies report on outcomes related to symptoms and treatment improvement (see Table 4). We grouped the outcomes into four clusters: treatment adherence; admissions; clinical recovery/symptom relief; and illness management.

Treatment adherence

Treatment adherence refers to the extent to which a person's behavior, e.g. taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations

Table 4: Outcomes in terms of symptoms and treatment improvement.

Treatment adherence	
Motivation & engagement with services	Schel et al. (2022), Weir et al. (2019)
Admissions	
Shorter admission/prevent admission	Taylor et al. (2018)
Easier transition from hospital to home	Hancock et al. (2022), Taylor et al. (2018), Thomson & Crossland (2019)
Clinical recovery/symptom relief	
Clinical recovery	Fallinn-Bennet et al. (2020), Levasseur et al. (2019)
Symptom relief	Cust et al. (2016), Smith et al. (2020), Theurer et al. (2021).
Illness management (knowledge, skills, strategies)	Barr et al. (2022), Hancock et al. (2022), Levvasseur et al. (2019)

from a health care or service provider. Two studies reported increased motivation and engagement, of respectively homeless participants and veterans (Schel et al., 2022; Weir et al., 2019).

Admissions

In three articles, the number or duration of admissions was used as an outcome measure (Hancock et al., 2022; Taylor et al., 2018; Thomson & Crossland, 2019). A peer support-led specialist group was associated with reduced service demand for participants with complex and concurrent psychiatric disorders (Taylor et al., 2018). All three studies indicated that experts by experience ease the transition from hospital to home and vice versa (Hancock et al., 2022; Taylor et al., 2018; Thomson & Crossland, 2019).

Clinical Recovery/symptom relief

In some studies interactions with the expert by experience had a positive impact on the clinical recovery of participants (Fallin-Bennet et al., 2020; Levasseur et al., 2019). Fallin-Bennet et al. (2020) state "most participants reported that their interactions with a peer support specialist had

a strong impact on recovery from perinatal opioid use disorder". Also, Levasseur et al. (2019) report that peer-driven family support services in the context of first-episode psychosis facilitated the overall recovery process. Specifically, symptom relief was indicated in a study conducted with mothers suffering from postnatal depression (Cust et al., 2016), in a study on PTSD (Smith et al., 2020), and in a study on community care (Theurer et al., 2021).

Illness management

Illness management, in terms of gaining knowledge, skills and strategies, was reported in three studies, for participants with borderline personality disorder (Barr et al., 2022), participants with complex mental health needs (Hancock et al., 2022) and for families during a family peer support group as an early intervention in psychosis (Levasseur et al., 2019). The latter included improved coping strategies, due to mutual support through sharing experiences; gains in knowledge of the illness and its treatment; emotional support; and increased caregiving and self-care capacities and skills.

Just positive outcomes?

A prominent finding was that nearly all studies reported exclusively positive outcomes. Only in two cases also negative outcomes were mentioned. Gopalan et al. (2017) stated that some participants said they felt overwhelmed by the peer support worker, which caused more stress. They also mentioned that the experts by experience promised to support participants in recreational activities, but did not have enough community knowledge to give appropriate support. Visa & Harvey (2019) found that some participants felt that the emotional support that was provided by the peer support worker was either not what they needed or did not have a lasting effect because their circumstances remained the same. In other studies, no negative outcomes were reported.

CONCLUSION AND DISCUSSION

With our scoping review, we aimed to map and synthesize what is known from qualitative research about the outcomes of interventions by experts by experience in (mental) health care and the social domain. We included 32 peer-reviewed articles, published in the period 2012 - June 2022. As the overall quality of the articles was modest (see also the section quality assessment), the results of this review should be interpreted with some caution.

Psychosocial outcomes stand out

When looking at the three outcome categories, it is evident that participants most frequently mentioned favorable psychosocial outcomes. Interventions by an expert by experience result in reduced feelings of loneliness and isolation, more hope for a better life, increased self-confidence, feeling more able to cope with issues and feeling understood. This is in line with the outcomes of other reviews (Cooper et al., 2024; Keuzekamp & Van Hoorn, 2022; Smit et al., 2023), in which most of the positive outcomes have to do with personal recovery, hope, empowerment, self-efficacy, and decreased self-stigma.

Remarkably, in the included studies the term 'recovery' is used mainly to refer to clinical recovery. Recovery was only sometimes used to refer to social recovery, which refers to the process of rebuilding and enhancing an individual's social roles, relationships, and community involvement (Shulamit, 2018) or personal recovery. A reason might be that 'recovery' is commonly used in mental health care, but not in the social domain or the field of somatic health care. Moreover 'recovery' is seldom a word used by service users themselves. We did see, however, that terms such as confidence and hope were often mentioned. Recovery can be seen as an overarching concept, under which hope and confidence are subthemes (Lloyd-Evans et al., 2014). So, while the term 'recovery' is not often mentioned in the articles, experts by experience do seem to contribute to recovery in a broader than clinical sense. This outcome is supported by other reviews (Cooper et al., 2024; Smit et al., 2023).

Outcomes on life domains

More than half of the articles report positive outcomes on life domains, especially on family relations, social contacts and community engagement. Other domains mentioned are: raising children, employment and education, daily routines and self-care, and finances. In line with this result, one of the other reviews (Cooper et al., 2024) also found positive outcomes on strength of interpersonal relationships and sense of community.

Remarkably, many domains were not put forward by the participants in the articles, such as housing, health, contact with the police and judicial authorities. One may wonder why these outcomes were not mentioned. Is it because of an expectancy bias, or because it is not important to them? This remains inconclusive based on the content of the articles included. In other literature, among which are the scoping reviews we studied for this article, no information is

found on these topics either. One of them (Keuzekamp & Van Hoorn, 2022) does mention this omittance, but also has not found a plausible explanation for this.

Outcomes in terms of symptoms and treatment improvements

These outcomes were mentioned in about one-third of the included articles, such as symptom relief and shorter admissions. The fact that this is the category with the least mentioned outcomes is especially interesting given that health insurance companies and other financiers hope peer work can contribute to improved outcomes on symptom relief and treatment and therefore reduce costs of care and support. Although this focus of insurers is understandable, it remains the case that from the perspective of service users there is clearly added value for their quality of life.

Interrelatedness of outcomes

While clustering the outcomes into three categories, the outcomes were clearly oftentimes interconnected. For example, Gregory et al. (2022) stated that positive outcomes concerning social connections contributed to feelings of acceptance, but also to not feeling alone (psychosocial outcome). In line with Gillard et al. (2015) and Evans (2023), we argue that the work of experts by experience is a complex intervention, not a one-dimensional treatment with which a specific one-dimensional problem can be solved. So, one would expect multiple interrelated outcomes.

No negative outcomes?

Many of the existing reviews on outcomes of the work of experts by experience, report on both positive and negative outcomes of peer support work (see the overview of Keuzekamp & Van Hoorn, 2022). Therefore, we also expected to find negative outcomes in the articles we included. Remarkably, that was not the case. In only three articles some negative outcomes were mentioned concerning the work of experts by experience. These findings might be attributed to differences in methodology. Most reviews concern quantitative studies in which predetermined outcome measures and scales are used, whereas in qualitative studies an open design is often used. Schel et al. (2022) reported that negative outcomes may have not been considered and/or may suffer selection bias. Indeed, it may be the case in many of the studies that these insights were not looked into or the researchers did not ask about negative outcomes. It is also realistic that participants mainly wanted to share socially desirable outcomes. Mentioning disappointments could be something they rather avoid.

Differences between domains

As most experts by experience work in the context of mental health and addiction, a substantial body of research relates to these domains. The other domains covered in the articles are very diverse, ranging from youth care to veteran care and from maternal care to long-term care. Making comparisons between these domains was not something we aimed for and would have been difficult given their heterogeneity. Considering that we found positive psychosocial outcomes in all articles, it could be argued that regardless of the domain, interventions by experts by experience are likely to have positive psychosocial outcomes. More research on what works for whom under which circumstances is still needed (see also Evans, 2023).

Implications

This review provides insight into the impact of the work of experts by experience on service users, based on qualitatieve research. Knowledge about the impact is important for experts by experience and service users, but also for other professionals, policy makers and health insurance companies.

We assumed that these studies provide a richer and more nuanced picture of the impact. In individual studies this is indeed the case, but that richness and nuance disappears at the moment of synthesis in a review article. Overall, the findings from the qualitative studies are in line with those from quantitative studies.

The results we found also call for critical reflection on how society frames the role and work of experts by experience. The impact question is part of a discours in which their contribution by definition is viewed from a contribution or benefit perspective. However, one may wonder whether 'impact' is the only valuable reason for the deployment of experts by experience. Or do they also have an intrinsic value? After all, they bring an important source of knowledge to healthcare and welfare, namely experiential knowledge. Support should benefit its users, so it is important to do justice to their lived experiences as much as possible. The fundamental recognition of experiential knowledge as a necessary source of knowledge is just as important in practice as the impact.

Another question that should be raised, relates to the outcome of the diversity and ambiguity of ways and roles we found. We were able to make an overview of whether it was an embedded

intervention or stand-alone and whether it was an individual or collective intervention (or both), but it remains unclear what the experts by experience do in more detail in practice. Therefore it was difficult to provide clear suggestions for practice implications.

Observational studies are necessary to get a clearer picture of (the context of) the work of experts by experience in different domains (e.g. Leemeijer, 2024) and the question how and why this diversity exists and what it means for the position of experts by experience in society. Also, we recommend paying attention to possible negative outcomes.

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