UNDERSTANDING THE IDENTITY OF LIVED EXPERIENCE RESEARCHERS AND PROVIDERS: A CONCEPTUAL FRAMEWORK AND SYSTEMATIC NARRATIVE REVIEW

"My fractured self was pieced together in my pursuit of my newly formed service user identity... I once had only a tiny seed of hope, now this has blossomed giving me a new sense of identity, purpose and direction." ~ Alison Bryant, Service user Advisor

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Abstract

Identity is how we understand ourselves and others through the roles or social groups we occupy. This review focusses on lived experience researchers and providers and the impact of these roles on identity. Performing roles simultaneously embodying professional and lived experiences contributes towards a lack of clarity to identity. This is not adequately explained by the theoretical evidence base for identity. This systematic review and narrative synthesis aimed to provide a conceptual framework to understand how identity of lived experience researchers and providers is conceptualised. A search strategy was entered into EBSCO to access Academic search complete, CINAHL, MEDLINE, PsycINFO, Psych Articles, and Connected papers. Thirteen qualitative papers were eligible and synthesised, resulting in a conceptual framework. Five themes explained identity positions: Professional, Service user, Integrated, Unintegrated and Liminal. The EMERGES framework, an original conception of this review, found themes of: Enablers and Empowerment, Motivation, Empathy of the self and others, Recovery model and medical model, Growth and transformation, Exclusion and Survivor roots contributed to lived experience researcher and provider identities. The EMERGES framework offers a novel way to understand the identities of lived experience researchers and providers, helping support effective team working in mental health, education and research settings.

KEYWORDS:

Background

There is a movement to integrate lived experience into professional domains with many mental health professionals now speaking out about their own mental health experiences (Adame, 2011; Fox, 2016; Richards, Holttum & Springham, 2016). Service user and carer involvement is a mandatory requirement for all Health Care Professions Council (HCPC) regulated healthcare training programmes in the UK, including, clinical psychology, social work, and mental health nurse training (HCPC, 2018). It was introduced after a commissioned review by HCPC into the benefits, facilitators and barriers to service user involvement from healthcare contexts (Chambers & Hickey, 2012). The sector finds service user involvement is integral to the effective training of healthcare professionals according to the British Psychological Society (BPS, 2010).

The involvement of lived experience researchers occurs in universities, through professional bodies such the BPS's Group of Trainers in Clinical Psychology (GTICP) involvement group and patient and carer representatives within the Royal College of Psychiatrists (RCPsych). The BPS's Division of Clinical Psychology (DCP, 2020) also released guidance on valuing the lived experience of trainee psychologists and how to integrate it into their work. Whilst healthcare professions' training and service improvement is informed through service user feedback akin to consumer and market led approaches (Noorani, 2013), disability activism is more concerned with emancipatory outcomes, achieving greater citizen control and rights for disabled people and survivors, led by democratic models (Beresford et al, 2004).

There is increasingly more participatory involvement in research and policy development within healthcare. In the UK, the National Institute of Health research (NIHR, 2020) provides guidance and mandates the process of involvement in research. Externally other research organisations in the UK such as McPin Foundation, National Survivor User Network (NSUN), Survivor Researcher Network (SRN) and Shaping Our Lives (SOL), to name a few, integrate and value lived experience. Due to the exponential growth in lived experience work, understanding how this work impacts people in these roles is essential.

Integration of lived experience in healthcare educational settings is achieved through the expert by experience role, where they act as "critical friends." Their involvement provides trainee healthcare professionals with insight into the challenges and experiences service users and carers have whilst navigating their mental or physical disability and of using services (BPS,

2010). The expert by experience role contradicts the traditional role of the service user and positions them as experts and people to learn from, as opposed to contexts where they are perceived as passive recipients of care (Fox, 2016). However, this contradictory positioning can be complex, leading to poorly understood identity constructions of lived experience researchers, and providers. Hodge (2005) identifies limits to patient and provider roles that are dichotomous and assimilated into experiential and professional knowledge bases exclusively. The identity of the lived experience researcher and provider do not clearly fit into these exclusive categories. The process of lived experience involvement may therefore give rise to novel formations of identity, requiring greater lucidity.

Benefits to integrating lived experience in mental health education and research results in empowerment (Omeni et al, 2014), improved empathetic responses from healthcare professionals, influencing mental health institutions to be person centred (BPS, 2010) and supports the learning of healthcare professionals (Schreur et al, 2015). Oliver et al (2019) describes the benefits of service user involvement but highlight the negative aspects of this work, including practical and personal risks to those engaged in this work. Resistance to the integration of lived experience by some service providers occurs through exclusion and tokenistic involvement (Cameron et al, 2019), queries over fitness to practice (DeRuysscher et al, 2019; Simpson et al, 2018; Wilson et al, 2018; Newcomb et al, 2017). In addition, sometimes there are queries regarding representativeness and authenticity of service users who are considered too professionalised (Andreasson et al, 2014). These roles can cause emotional burden to those that perform them (Faulkner & Thompson, 2020).

Further barriers to meaningful integration of lived experience can occur for several reasons. Service providers may want to maintain positions of power, they may lack experience in this type of work, or involvement may be at odds with the models within which they work, such as the medical or recovery model. Service providers may lack funding for these roles or may have negative views on the benefits of lived experience, or even their subjective conceptual understanding of what it means to integrate lived experience (Tambuyzer, Pieters & Audenhove, 2011; Bee, Price, Baker & Lovell, 2015).

These illustrations of risk to the lived experience researcher or provider, suggest the role may be unsafe and cause harm. Richards et al, (2016) reported that the mental health sector is not yet ready or safe regarding integration of lived experiences. It is essential, and of great ethical necessity, that service providers do not cause harm to service users in these contexts.

These roles, in which there is integration of lived experience in professional spaces, is likely to impact identity; an under researched area.

The theoretical basis of Identity

Research on identity of healthcare professionals has tended to focus on the development of professional identities in, for example, medical students (Goldie, 2012; Cruess et al, 2015), nurses (Johnson et al, 2012), clinical psychology trainees (Mcelhinney, 2008), and social workers (Wiles, 2017). This research identifies the importance of clarity regarding identity, resulting in better team working, wellbeing and resilience. Additionally, experiences of mental illness, such as Psychosis, also influence changes in identity (Conneely et al, 2020). Mental illness and disability are the basis for undertaking lived experience researcher and provider roles and so it is essential to understand how these roles might further influence identity.

Identity theories suggest identities are formed via group membership (Tajfel & Turner, 1979) or the roles we occupy (Stryker, 1980), and intersectional (Crenshaw, 1989) and liminal (Turner, 1969) processes. For example, Social Identity theory (Tajfel & Turner, 1979) can be used to explain the service user identity, who may self-define with an expert by experience group as their in-group, and from which they begin to share similar values, beliefs, and behaviours. They identify differences between themselves and others. Experts by experience within clinical psychology may find themselves in opposition to psychiatry. Tse, Cheung, Kan, Ng & Yau (2012) find service user involvement provides the right context to lead to changes in identity. Social Identity theory suggests identities are formed in opposition to other social identities. However, the theory does not account for simultaneously occupying the oppositional positions of lived experience and professional identities.

Identity theory (Stryker, 1980) suggests identity is drawn through the roles we occupy in a structured society. Individuals attribute meaning and expectations to these roles through interactions with others. We seek to preserve the clarity of one's own role, resulting in more certainty and satisfaction with our own identities (Thoits & Virshup, 1997). The role of the lived experience researcher and provider, that spans both patient and professional, results in contradictory meanings which are likely to be unsatisfactory, due to a lack of clarity. This suggests a complexity to these roles that identity theory cannot account for.

Liminality (Turner, 1969) better accounts for 'in between states.' Liminality is understood as "a position of ambiguity and uncertainty" (Beech 2011; p. 287). The concept describes the role of peer workers and peer researchers (Simpson et al, 2018; Faulkner &

Thompson, 2020). Liminality may be useful in explaining lived experience roles. Although, the concept undermines the complexity of the lived experience researcher or providers' identity due to the suggestion of an absence of identity.

Intersectionality, (Crenshaw, 1989) refers to the intersecting personal elements of an individual such as race, gender, class, ethnicity, sexuality, and others, that in conjunction with each other, compound the experience of discrimination. Mental health identities and professional identities may also be influenced by intersectionality, suggesting the role may be burdensome. Additionally, Liminality (Turner, 1969), may also be burdensome, and interact and impact identity, similarly to the process of intersectionality.

The theories do not explain the identity of lived experience researchers and providers. Considering lived experience researcher and provider roles are increasingly common, a better understanding of how these roles impact identity is required. This will support others to better understand those in these roles, encourage better team working and identify influencing factors relating to the formation of identity.

Systematic reviews have focussed on service user involvement, the process of involvement and, but to a lesser extent, on the impact of involvement on learning and clinical skills (Repper and Breeze, 2007; Terry, 2012; Happell et al, 2014; Townend et al 2008). A systematic review and conceptual framework of recovery of mental health patients has been conducted (Leamy et al, 2011), a conceptual understanding of identity changes in psychosis (Conneely et al, 2020), and a literature review into service user involvement and identity (Emery, 2015). However, currently there is limited research into identity formation of lived experience researchers and providers and no systematic review that provides a synthesis and conceptual framework of factors relating to identity development of lived experience researchers and providers in mental health, education, or research.

Objectives

The aim of the review is to identify how identity has been conceptualised in relation to lived experience researchers and providers in mental health, education and research settings.

Methodology

Conditions or domain being studied

The systematic review explored lived experience researchers and providers and how their identities were impacted by these roles in mental health, education, and research.

Positionality and Reflexivity

The review was conducted by VG, PhD researcher, and PF, LG, BG, Clinical psychologists, and CE, research psychologist. VG is also an expert by experience for two involvement groups for clinical psychology programmes and is a service user advisor to national research projects related to their own individual experiences. The research team see this as a strength but are aware of the potential biases each of their own experiences may cause in relation to the design and analysis of the research. This was mitigated by themes and findings of this review being discussed as a team. The review held pragmatism as its epistemology to understand findings and collate studies that differed in methodologies and philosophical perspectives. SA and RQ were independent PhD students each with their own lived experience and academic knowledge contributing to quality appraisal alongside VG. Service user advisor AB also brought her own lived experience to help assess validity of the findings.

Table 1. Search strategy

1.	Service user involvement OR Service user participation OR Service user engagement OR Service user advisors OR Expert by experience involvement OR Expert by experience participation OR Expert by experience engagement OR Expert by experience advisors OR Patient involvement OR Patient and Public Involvement OR Patient and Public participation OR Patient and Public engagement OR Patient and Public advisors OR Service user and Carer involvement OR Carer involvement OR Carer participation OR Carer advisors OR Coproduction OR Collaboration OR Peer worker OR Peer support OR Peer researchers OR Peer engagement OR Peer participation OR Peer involvement Or Survivor researcher OR Survivor participation OR Survivor involvement OR Survivor engagement
2.	Clinical psycholog* OR Social work OR Mental health nurs* OR Research OR Service provider OR Mental health professional
3.	Training OR Education OR Mental health education
4.	Identity OR Mental health identity OR Service user Identity OR Recovery Identity OR Illness Identity OR Dual Identity OR Becoming OR Identity construct
This search strategy was put in place with and/or terms as follows: 1 and 2 and 3 and 4.	

Information Sources

The search strategy was co-created as a team and with a university librarian, detailed in Table 1, which was inputted into the University of Liverpool database, on 21st November 2021 and rechecked on 17th May 2022 using EBSCO to access journals from Academic search complete, CINAHL, MEDLINE, PsycINFO, Psych Articles, and University of Liverpool Catalogue was used for this. Hand searching of references from papers was conducted. Connected papers website was used to search for related papers. Figure 1 reports the selection procedure.

Selection process

VG initially assessed eligibility of studies. Where there were queries over eligibility the supervisory team were consulted, PF, CE, LG, and BG.

Table 2. Eligibility and Inclusion and Exclusion criteria

(SPIDER tool for qualitative research, Cook et al (2012)

		Inclusion criteria	Exclusion criteria
S		**Sample** Population of sample were lived experience researchers and providers (defined as those with mental or physical disability). Mental or physical disability are not specified. Participants aged 18 years old and above	
		Lived experience researcher and providers who may also be referred to as experts by experience, peer researchers, co-researchers, lived experience researchers, service user researchers, disability researchers, survivor researchers and/or practitioners with lived experience including mental health professionals with mental or physical disabilities and also peer support workers and peer workers. In the context of mental health, education and research	Lived experience researchers and providers in the context of physical healthcare conditions and contexts outside of mental health, education and research. Medical students and medical doctors.
PI		**Phenomenon of Interest** The study had to explore the effect lived experience researcher and provider roles on identity	Studies that did not focus on the effect of lived experience roles on identity. Studies on identity in relation to aspects of identity such as LGBT, gender, social class and ethnicity, national and political. Studies that used Erikson's model of identity development and Freud's Id, Ego and Superego theory.
D		**Design** Qualitative interviews, not limited by design, methodology or philosophical epistemology	
E		**Evaluation** Conceptualisation of identity, causes, effects, related factors, sample size, year published, methodologies, philosophical epistemology, key findings and study location. Published in the English language but not limited by country of origin.	
R		**Research type**	Purely theoretical or conceptual papers

	Peer reviewed studies Qualitative empirical studies Published between January 2000 and May 2022	

Data items

The characteristics of the studies, type of study, method used, sample size, participant demographics, research aims, and findings were extracted. More specifically, effects and impact of lived experience researchers and providers' work on identity were extracted through preliminary summaries and themes extracted of each study.

Synthesis methods

The review followed the PRISMA (2020) protocol for conducting systematic reviews. The modified version of Popay et al (2006) stages of developing a conceptual framework was applied to the synthesis. The stages were 1) Develop a preliminary synthesis of findings, 2) Explore relationships in the data within and between studies and 3) Assess the robustness of the synthesis. The review followed protocol to conduct the review, published on Open Science Framework (Gupta, 2021) osf.io/f4h8p

Stage 1 Preliminary synthesis

This stage involved tabulation and a thematic analysis of the identity of lived experience researchers and providers. An overview of the characteristics and themes of each study are in Table 3. This preliminary synthesis informed the development of a coding framework and each article within the review inductively coded to identify additional themes, using NVIVO.

Stage 2 Exploring relationships within the studies

The studies were assessed for similarities and differences to identify emerging themes that explain identity. The studies in the three different settings, mental health, education and research, were analysed separately and the results were compared and synthesised to see if the research areas held different or similar conceptualisations of identity, and these supported in translating the initial synthesis into a conceptual framework.

Stage 3 Certainty assessment: Checking the robustness of the synthesis

Quality appraisal was conducted using Joanna Briggs Institute (JBI) critical appraisal

tool (Lockwood, Munn, Porritt, 2015) by three independent researchers, VG, SA and RQ, using the same procedure and variation discussed until consensus reached. The reviewers were each PhD researchers and two of these reviewers with lived experience. To understand the robustness of the synthesis service user advisors (1), lived experience researchers (3), and academic mental health professionals (3) were consulted to see whether the conceptual framework fitted with the way they understood their identities as lived experience researchers and providers. The purpose of this was to check the validity of the conceptual framework. This is evidenced through a reflective account by Service user Advisor, AB.

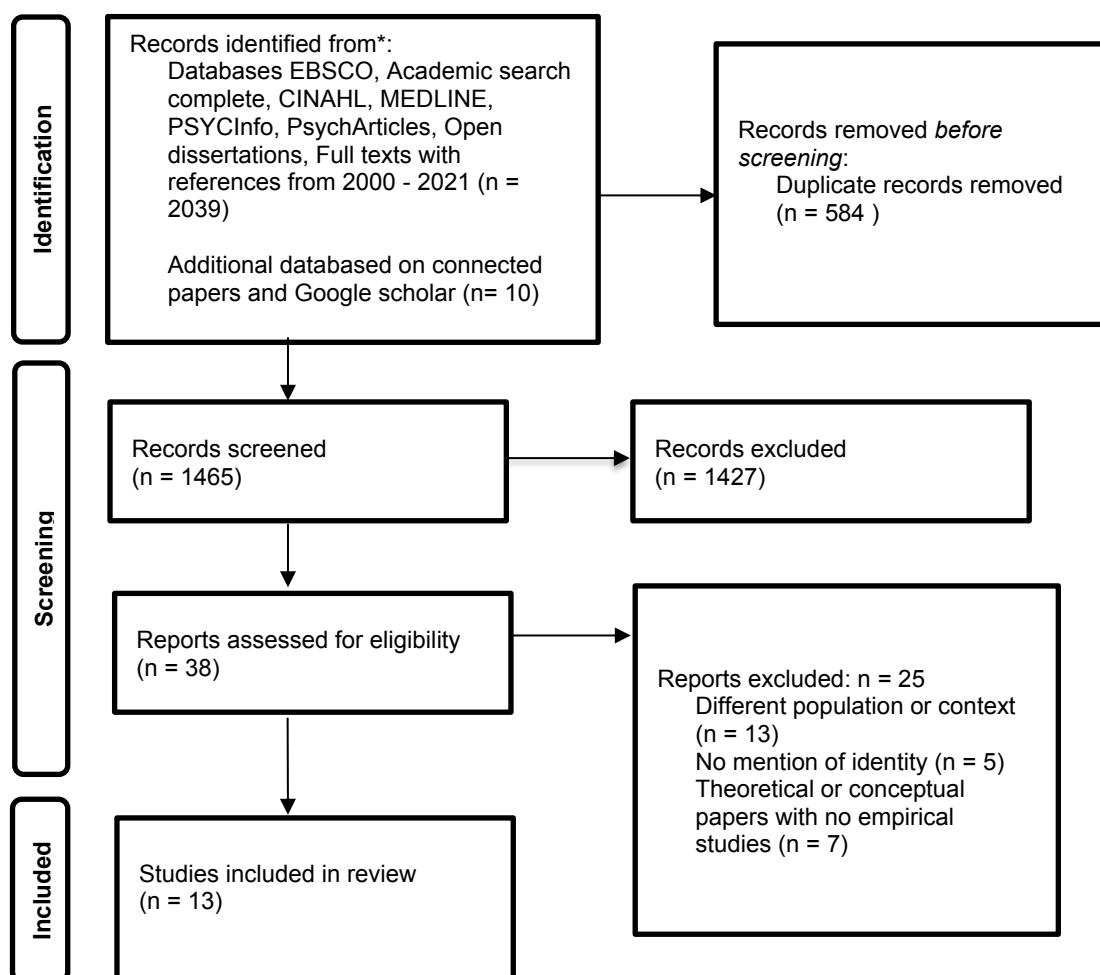**Figure 1: PRISMA Flow diagram of selection process**

Table 3. Stage 1 A preliminary synthesis

First Author (Year)	Aims	Study population					Method	Summary of findings and core themes relating to identity
Adame (2011) USA	To explore the implications of being a survivor and mental health professional and the impact on identity	5 participant interviews of therapists who are also survivors.	Age not reported.	Gender not reported.	Ethnicity not reported.	Type of mental illness not reported.	Holistic content analysis.	Themes identified the foundational nature of the survivor identity. Risks and benefits of self disclosure of lived experience were identified. They find they have a greater understanding of their patients but also identify a risk of overidentification. Us and Them divisions were found between survivors and professionals. Differences between psychiatric and psychological models was also discussed.
Newcomb et al (2017) Australia	To explore how social work and human services students with service user experience integrate their lived experience in training.	20 Undergraduate Social work and Human services students who had accessed services.	Age not reported.	Gender not reported.	Ethnicity not reported	Type of mental illness not reported.	Inductive thematic analysis	Five key themes; motivation to enter social work and human services due to personal experience as a service user and a motivation to help others like themselves. There was also the idea of positive role modelling and supporting others in ways they have been supported. The idea of being unfit to practice stopped disclosures. Both service user and service provider identities were not easily integrated.
Richards et al (2016) UK	To explore identity of mental health professionals with mental health service user experience	10 participants who were mental health professionals with experience of being a service user.	Age not reported.	5 male and 5 female.	7 White British, 2 Asian, 1 South African.	Type of mental illness: depression, suicidal ideation, paranoia, schizophrenia, Bipolar disorder, Psychosis, Anxiety and Bulimia.	Discourse analysis A social constructionist epistemology	Themes found included separate unintegrated and integrated identities of "Professional" and "Patient." Discourse on Professional identity attributed power, knowledge, and expertise whereas Patient identities were perceived as stigmatised, influencing a lack of disclosure. Integrated identities led to a new sense of self. Integration of mental health patient identities and professional identities gave new skills and power.
Simpson et al (2018) UK	To explore the occupational and liminal identities of peer support workers	8 Peer support workers and 13 Service users	Age range between 20 and 55 years old	5 male and 3 female peer support workers 8 male and 5 female service users	White Irish, White other, Bangladeshi, Black Caribbean, White British, White other, Black British, Black African, Mixed, Black/British African and Black European	Service user mental illnesses reported but not peer support workers Depression, Paranoid Schizophrenia, Psychosis, Unknown, Schizoaffective disorder	Thematic analysis with deductive application of Liminality theory	The analysis revealed lived experience influenced service users to better connect with peer support workers who were like them and understood them and who were able to model recovery. The role supported in fostering a new identity and motivation to move past the service user identity. Occupational training and learning new skills legitimised occupational identity. Relationships with peers had positive effects and likened to a friendship but were also confusing. Peer worker identities were somewhere in between service user and professional, leading to liminal identities.

| Wilson et al (2018)

Canada | To identify challenges of peer workers and provide recommendations based on emerging themes of identity | 11 peer workers and 6 informants were interviewed.

Peer workers who are previous drug users supporting drug users in harm reduction. | At least 18 years of age | 4 Male informants and 2 female informants

4 male and 7 female Peer workers | Ethnicity not reported. | Previous or current drug users, but other mental or physical disabilities not reported | Grounded theory analysis and symbolic interactionist analysis. | The drug user and peer worker identities were perceived as distinct. The identities of peer workers relied on the idea that they were in recovery and no longer using drugs, impacting disclosure and health seeking behaviour. The second theme was that of Triggering, where the role often made it difficult for the peer worker to remain well. There was pressure to perform, and they held themselves to a certain expectation they perceived a peer worker should be held to. The role also meant that they were stuck with the stigmatising drug user label in their peer working roles. |
|---|---|---|---|---|---|---|---|---|
| Toikko (2016)

Finland | To understand the learning process behind becoming an Expert by Experience. | 12 participants Mental health service users that become experts by experience | Age range 28 - 57 years old. | Gender of participants unclear. | Ethnicity not reported. | Type of mental illness not reported. | Thematic analysis | Four different themes. 1. Creating distance from experience: This meant having distance from the emotion of mental health experiences through storytelling. 2. Sharing experiences with peers and friends: this process describes how listening to the stories of others and sharing experiences facilitated recovery 3. Combining experiences with existing competences and skills learned through previous professional roles or personal experiences were formative to identity. 4. The roles also led to developing an orientation to the future. |
| Jones et al (2020)

Finland | To explore the identities of service users who become Experts by experience. | 13 participants, Service users and/or Carers that are Experts by experience. 11 of which has mental illness. | Age range 23 - 62 years old | Gender not reported. | Ethnicity not reported. | Type of mental illness: Bipolar disorder, Schizophrenia, Psychosis and Depression. | Thematic analysis | Being an expert by experience helped to reframe lived experience through constructing and sharing stories, creating distance from it. Illness experiences were sources of motivation to change their narrative to recovery with opportunities for self-discovery and personal development. The illness identity was constructed as being in the past and recovered identities in the present. Professional identities were constructed through learning new skills and combining them with existing skills to elevate their status. Social connections and collective shared grievances motivated politicised identities. |
| Hutchinson et al (2013)

UK | To describe the identities of service user researchers and the effects on identity. | 6 Co-researchers interviewing 30 services users. Mental health service users and co-researchers that are also mental health service users. | Age range 30 - over 65 years old | 5 Female and 1 Male | Ethnicity not reported. | Type of mental illness: Bipolar Disorder, Depression, Anxiety Disorder, Postnatal Depression and Eating disorder. | Interpretive Phenomenological analysis | Two themes were found within the research of co-researchers connecting with the service users' stories. There was an idea of unrestricting lives and reciprocity. This theme represents connections with others and feeling belief in themselves through belief from others in you. Hearing others' stories enabled empathetic connections. The second theme was reframing the illness narrative, where the process of hearing other people's stories of mental distress humanised the people behind the diagnosis. The medical model made individuals feel inferior but involvement as co-researchers empowered them. |

Cameron et al (2019) UK	To understand the impact of service user involvement on identity.	22 disabled individuals who are service user researchers	Age range Under 40 to 70 years old	12 women, 9 men and 1 nonbinary.	Ethnicity not reported	Type of impairment: sight loss, being deaf, acquired brain injury, cognitive impairment, learning disability, mental illness, non-epileptic seizures, multiple sclerosis, cerebral palsy, mobility impairment, wheelchair users and Carers	Thematic analysis	Involvement as experts by experience was found to give them more power but was sometimes tokenistic. The same individuals when perceived as service users held different levels of power, respect, and value. Good outcomes and meaningful involvement lead to empowerment, purpose, feeling valued, and validated, gaining new skills, knowledge, and social connection. However, service providers unintentionally oppress experts by experience through reverting back to medical model approach that diminishes identity and power of experts by experience.
De Ruysscher et al (2019) Belgium	To understand the recovery process of a patient who becomes a peer worker.	1 Peer worker and expert by experience	Age not reported.	Gender 1 male peer worker and 1 female academic researcher.	Ethnicity not reported.	Type of mental illness: Paranoid delusional psychosis, drug addiction	Bricolage method with a thematic analysis	Four themes found including 1) Life rebuilding encompassing ideas of living a meaningful life with responsibilities such as having a job, hobbies. Social circles were seen as essential in rebuilding life because of stigma and discrimination, 2) The patient identity was seen as salient when undergoing treatment and stigmatised. 3) Continuity of care, and person-centred care were essential to effective service provision and recovery. 4) The role of drugs theme explained that it was difficult to disclose and seek help when relapsing due to the expectations of the peer worker role and stigma of drug use.
Faulkner & Thompson (2020) UK	To identify the emotional impact of lived experience work, effects on identity and challenges and benefits and methods to support these researchers.	10 lived experience researchers	Age not reported	Four male and 6 female.	Ethnicity, 8 White, 2 South Asian.	People with lived experience at various levels and stages in their roles. One had a physical disability.	Thematic analysis	Themes found the idea of negotiating identities of lived experience researcher in their roles and showed there was emotional burden and labour associated with embodying lived experience roles and they found experiences of alienation and exclusion in research and how they had to navigate the bureaucracy of the systems and they identify support strategies within their key findings.

Hill, Tickle & DeBoos (2021) UK	To explore personal effects of involvement as service user and carer representatives within clinical psychology training	14 service user and carer representatives	Ages 25-79 years old	6 Male 8 Female	Ethnicity White British, British, Asian British, British Indian, Mixed, Italian, German Syrian	Type of mental illness or disability not reported but type of services accessed reported	Thematic analysis with critical realist approach and deductive application of psychological theory	5 themes including Theme 1: Environment determines sense of safety including the influence of supportive relationships in the team and by staff. Theme 2 was about "meeting challenges" and feeling empowerment and a sense of belief in the self. Theme 3 was about gaining a sense of purpose through being listened to and making a difference. Theme 4 was about "The person you see now is not the person I was," and Theme 5 was about "breaking the glass ceiling" and a sense that involvement was controlled by staff.
Cooke, Daiches & Hickey (2015) UK	To explore the narratives of experts by experience of people with personality disorders delivering training	8 Experts by Experience	Age ranges from 25-65 years old	8 Female	Ethnicity were all White	Borderline personality disorder	Narrative analytical framework and holistic analysis Social constructionist approach	Themes found were termed chapters. Chapter 1 detailed the "screaming in a milk bottle" theme identifying acute experiences prior to becoming an expert by experience where their needs were not always visible or heard. They were also excluded from life changing decisions regarding treatment and diagnosis. Chapter 2 was a turning point where they understood their experiences because of problems with services and not themselves. Chapter 3 was about taking up the expert by experience role and how it turned experiences into something positive. Chapter 4 also discusses the emergence of the professional identity where they gain more power and value. Chapter 5 talked about impact on the self and others resulting in self-worth, and self-esteem.

Table 4. Mode responses to quality appraisal

JBI Quality appraisal checklist for qualitative research	Adame (2011)	Newcomb et al (2017)	Richards et al (2016)	Simpson et al (2018)	Wilson et al (2018)	Toikko (2016)	Jones et al (2020)	Hutchinson et al (2013)	Cameron et al (2019)	DeRuysscher et al (2019)	Faulkner & Thompson (2020)	Hill et al (2021)	Cooke et al (2015)
1. Is there congruity between the stated philosophical perspective and the research methodology?	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2. Is there congruity between the research methodology and the research question or objectives?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3. Is there congruity between the research methodology and the methods used to collect data?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
4. Is there congruity between the research methodology and the representation and analysis of data?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
5. Is there congruity between the research methodology and the interpretation of results?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6. Is there a statement locating the researcher culturally or theoretically?	✓	✗	✓	?	?	?	✓	✓	✓	✓	✗	✓	✓
7. Is the influence of the researcher on the research, and vice versa addressed?	✓	✗	✓	✗	✓	✗	?	✓	✓	✓	✗	✓	✓
8. Are participants and their voices adequately represented?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
9. Is the research ethical and according to criteria for recent studies and is there evidence of ethical approval by an appropriate body?	✗	✗	✓	✓	✓	?	✓	✓	?	✓	✓	✓	✓
10. Do the conclusions drawn in the research flow from the analysis or interpretation of the data?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Results

Of the 1465 articles screened, thirteen articles met the inclusion criteria, as shown in Figure 1. These were published between 2011 and 2022 and originated from USA, Australia, UK, Canada, Finland, and Belgium, and sample size of the studies ranged from 1 to 46 participants. These studies explored the identities of mental health professionals who were also survivors or service users (Adame, 2011; Richards et al, 2016); the identities of peer workers (Simpson, 2018; Wilson, 2018; DeRuysscher, 2019) social work students (Newcomb et al, 2017) service user researchers, experts by experience and co-researchers and peer researchers (Toikko, 2016; Jones, 2020; Hutchinson & Lovell, 2013; Cameron et al, 2019; Faulkner & Thompson, 2020; Cooke, Daiches & Hickey, 2015) and service user and carer representatives (Hill et al, 2021). All studies were qualitative but varied in methodology, epistemology, and analysis and so a pragmatic approach was used to synthesise different approaches. One of the studies was part of a randomised controlled trial and another part of a pilot study and all, empirical qualitative studies. A synthesis of the findings follows, followed by a translation of these findings into a conceptual framework.

Quality appraisal

The Joanna Briggs Institute (JBI) (Lockwood, Munn, Porritt, 2015), quality appraisal tool for qualitative research was used to assess the quality of each paper using 10 items that were scored as yes, unclear, and no regarding quality. Three independent researchers assessed the 13 papers. Following discussion over differences in ratings, consensus was reached. Fleiss' Kappa interrater agreement was moderate, k = .485, p<.001. Kappa agreement for ratings of No, k = .769, p <.001, Yes, k = .554, p <.001 and Unclear, k = .184, p < .001. The mode quality appraisal ratings can be seen in table 4. Ethical approval was not stated in some studies (Adame, 2011; Newcomb, 2017; Cameron et al, 2019). There was some bias in the recruitment process (Adame, 2011). Each of the studies lacked diversity in their sample regarding ethnicity and gender. 8 studies did not report demographics on ethnicity (Adame, 2011; Newcomb et al, 2017; Wilson et al, 2018; Toikko, 2016; Jones, 2020; Hutchinson & Lovell, 2013; Cameron et al, 2019; DeRuysscher et al, 2019). 3 studies did not report gender (Adame, 2011; Newcomb et al, 2017; Jones, 2020) and 1 study reported this ambiguously (Toikko, 2016) and Cooke et al (2015) included a sample of only white females. Age was not reported in 5 studies (Adame, 2011; Newcomb et al, 2017; Richards et al, 2016; DeRuysscher et al, 2019; Faulkner & Thompson, 2020) and 1 study reported that participants were of adult age but no descriptive statistics were included (Wilson et al, 2018). Each of the studies varied in philosophical

approaches and methodologies. There were also limited statements identifying the researchers' own positionality in relation to the research, either theoretically or culturally, (Newcomb et al, 2017; Faulkner & Thompson, 2020) and it was unclear in 3 studies (Simpson et al, 2018; Wilson et al, 2018; Toikko, 2016) and very limited acknowledgement of the researcher's impact on both the research and vice versa, which was not identified in 4 studies (Newcomb et al, 2017; Simpson et al, 2018; Toikko, 2016; Faulkner & Thompson, 2020). Different lived experience researcher and provider roles were treated as a homogenous group within 2 studies (Adame, 2011; Richards et al, 2016). All but one study allowed for heterogeneity regarding type of lived experience of mental or physical disability. Cooke et al (2015) only included people with a personality disorder diagnosis. 2 studies were heavily theoretically driven without the researchers acknowledging the deductive approach they used and its influence on findings (Simpson et al, 2018; Hill et al, 2021).

Stage 2: Exploring relationships within the studies

Through the process of stage 1, synthesising studies of lived experience researchers and providers in mental health, education and research, summarising, tabulating and critically appraising. Five main themes of identity positions were identified and seven themes relating to identity development. The following section explores these themes and their similarities and differences across the studies. Table 5 details each theme and how the studies contribute to the development of the framework.

Table 5. A Translation of findings into a conceptual framework

Positions of identity and causal factors	Studies and their original conceptions
Professional	Newcomb et al (2017) Positive/Negative role modelling; Richards et al (2016); Simpson (2018) Occupational training. Wilson (2018) Peer worker. Toikko (2016) Combining experiences with existing competences. Jones (2020) Competences and skills. Use of existing skills in involvement work (Hill et al, 2021). (Cooke et al, 2015)
Service user	Richards et al (2016) Wilson (2018) Drug user. Cameron et al (2019) disability identity locates problem in individual, activists reframe this to society not meeting their needs and being the reason for impairment. Cooke et al (2015)
Integrated	Richards et al (2016) Personhood; Adame (2011) Benefits of disclosure: Newcomb et al (2017) Personal experiences help professional identity. Embodied experiences (Faulkner & Thompson, 2020)
Unintegrated	Richards et al (2016) Adame (2011) Risks of disclosure; Newcomb et al (2017) Disclosure difficulties, Not easily integrated. Reluctance to share lived experience (Cooke et al, 2015) Toikko (2016) Creating distance from experience. Alienation (Faulkner & Thompson, 2020)
Liminality	Simpson (2018) Liminality of PSWs. Faulkner &Thompson, 2020)

Empowerment	Simpson (2018) Occupational training leads to competence, empowerment, skills, knowledge. Toikko (2016) Developing an orientation to the future and politicised identities. Jones (2020) politicised identities through shared grievances and collective identity. Hutchinson & Lovell (2013) Reframing of illness, sharing experiences and listening to each other's stories enabled and empowered co-researchers to be less critical of the self and normalise experiences of distress. Cameron et al (2019) Good outcomes of involvement lead to empowerment, purpose, value, skills, and knowledge. DeRuysscher et al (2019) Life rebuilding. Disempowering through the system and bureaucracy but enablers through personal, collective, work, and system level strategies (Faulkner & Thompson, 2020) Hill et al (feeling listened to, valued and with purpose and making a difference. Cooke et al (2015) impact on self and others.
Motivation	Newcomb et al (2017) Simpson (2018) Model recovery and inspire others. Toikko (2016) Motivation to share experience and reduce stigma/raise awareness. Jones (2020) Motivation to move from illness identity to a positive one. Cooke et al (2015) Taking up the trainer role - It just all took off.
Empathy of the self and others	Simpson (2018) (Identity and relationships, connection with peers); Wilson (2018) Drug talk can be triggering. Toikko (2016) Sharing experiences with peers and friends. Jones (2020) Sharing of experiences leads to common shared experiences and politicised identities. Hutchinson & Lovell (2013) Unrestricting lives and Reciprocity - connections with others affirmative experiences and belief in others and the self, hearing others' stories enabled empathic connections and normalised experiences of distress. Cameron et al (2019) find that social connections are a result of involvement. Hill et al (2021) being understood by trainees and feeling connected to each other as survivors. "Band of brothers" (Cooke et al, 2015)
Recovery model/Medical model	Adame (2011) Differences between psychological and psychiatric models; Richards et al (2016) Jones (2020) Cameron et al (2019) service providers do harm when reverting to the medical model lens and resulting in diminished identities. Decisions, diagnoses being made for them in secrecy (Cooke et al, 2015)
Growth and Transformation	Richards et al (2016) Personhood; Jones (2020) Becoming an EBE changed illness identity to a more positive one. Hutchinson & Lovell (2013) process of hearing others' stories humanised the experience of distress and transformed and reframed service user identities. Hill et al (2021) I am not the same person I was. Emergence of professional identity linked to value and power (Cooke et al, 2015)
Exclusion/Stigma and Discrimination	Richards et al (2016) Unintegrated; Adame (2011) Us and Them divisions; Newcomb et al (2017) Disclosure difficulties. Simpson (2018) Identity and relationships (PSWs Excluded by other professionals). Wilson (2018) Barriers to accessing services when relapsing as a PSW, Difficult to move beyond Drug user identity to professional opportunities. Jones (2020) Cameron et al (2019) service providers choose who is listened to and who has power. Alienation and exclusion of diversity in white spaces (Faulkner & Thompson, 2020). Hill et al (2021) breaking the glass ceiling. Information, diagnosis of personality disorder not shared (Cooke et al, 2015)
Survivor roots	Richards et al (2016) Adame (2011) Foundational nature of survivor identity. Jones (2020) Cameron et al (2019) Screaming in a milk bottle (Cooke et al, 2015).

The Positions of Identity

Five identity positions became apparent; each of these is described below.

Service user and Survivor identities

Service user and survivor identities were common across all studies. The data identified service users, survivors, drug users and experts by experience. These identities were separate to the service provider and held less power, control, and respect. Cameron et al (2019) reported that services perceived the service user or disabled person as the one with a problem. Their identities are also perceived as "limiting" (Newcomb et al, 2017, p 2). DeRuysscher et al (2019)

also found that service users were defined and overshadowed by their service user identities. Service user involvement work provided the opportunity to transform these identities and move beyond the stigma associated with it to more positive identities not rooted in deficit (Hutchinson & Lovell, 2013). The idea of role reversal, where the service user became the provider through the expert by experience role, changed the power differentials and enabled service users to be seen as people to learn from (Toikko, 2016).

Professional Identity

Across the 13 studies the professional identity of lived experience researchers and providers was constructed. This consisted of having skills and competences to effectively carry out these roles (Cameron et al, 2019) and motivation to combine existing competences from personal lives into professional roles (Toikko, 2016). Richards et al (2016) found those with professional identities were seen as knowledgeable, and competent, with more power than those with just service user identities. Peer workers were focused on developing professional identities which were legitimized through training (Simpson et al 2018) and appropriate titles (Jones, 2020). There were allowed and disallowed characteristics, such as it "not being acceptable to become angry" (Richards et al, p 6), "having everything together" and "never having a bad day" (Wilson et al, 2018, p363). Jones (2020) reported, being an expert by experience required that one must communicate articulately and clearly. Cooke et al (2015) find that the development of a professional identity shifted service users to feel as though they have greater value and power. Within these studies it was reported that service user researchers and providers were more likely to want to convey their expertise as people with knowledge who were skilled at their jobs to detract from their stigmatised service user identities.

Integrated identities

Integrated identities were discussed within the research as individuals holding service user and professional identities simultaneously, and this was problematic and conflicting for the individual. There were differently held beliefs of whether integration was useful or not. Richards et al (2016) found within an "integrated" identity, participants drew on all their identities to inform their practice, but this was rarer than the unintegrated identity as it was more difficult to accomplish. Newcomb et al (2017) found when academics shared their lived experience in professional contexts it reduced stigma and provided student healthcare providers with examples of how to integrate their own lived experiences. However, Adame (2011) found integrating lived experience excluded them from being accepted by colleagues within the

profession and by other survivors of the mental health system. The idea of integration was spoken of as embodiment but was emotionally burdensome in peer researchers (Faulkner & Thompson, 2020).

Unintegrated

This theme addressed the issue of being unable to hold identities of service user and professional simultaneously. Richards et al (2016) reported the "mad man versus someone who got a reputation for being highly professional they're worlds apart unfortunately." (Richards et al, 2016, p7). Service user and professional identities were understood as separate and either good or bad. Adame (2011) found that, despite mental health professionals having personal experience of mental illness they were likely to keep that hidden. Cooke et al (2015) also find that being perceived as the one with lived experience in the room was conflicting, leading to a reluctance in wanting to share. Newcomb (2017) reported this was due to stigma and fear over queries over fitness to practice. This fear stopped some peer workers from seeking help when they relapsed (Wilson et al, 2017). Cameron et al (2019) also identified the conflicting positions experts by experience occupy, where in one context they are sources of knowledge, and other contexts as consumers of care. The service user representative role required service users to share their stories but with an expectation to separate the emotion from storytelling, to create distance from the service user identity to support learning from experience that could be tolerated by healthcare professionals (Toikko, 2016; Faulkner & Thompson, 2020; Jones et al, 2020).

Liminality/Ambivalence

The concept of liminality (Turner, 1969) posed by Simpson et al (2018) and Faulkner & Thompson (2020) described the experiences of peer workers who occupy a space in between being a service user and professional. The role ambiguity through occupying in between identities meant that it was difficult for peer workers to understand how they should interact with the people they support and the teams they work in. There was a lack of understanding whether they were friends or peers or a different dynamic. This had consequences for how others perceived them, and unclear expectations of the role and services they provided. This identity ambiguity led to differences in respect and power associated with these roles. This posed similar dilemmas to the lived experience researcher holding ambivalent identities (Faulkner & Thompson, 2020).

The EMERGES framework

The data in the studies informed the EMERGES framework that were found to be themes relating to identity development, encompassing: Empowerment, Motivation, Empathy of the self and others, Recovery model and medical model, Growth and transformation, Exclusion and Survivor roots. The framework is illustrated in Figure 2. This is presented in reverse and ascending order starting from survivor roots through to enablers and empowerment replicating the journey that the current research suggests lived experience researchers and providers go through to develop their emerging identities.

Survivor roots

Adame (2011) found the survivor identity were the roots and drivers of their need to work in the system. "The survivor part of me is what gets me out of bed each morning, and thinks that what I'm doing is important, and meaningful, and really needed…Like this background motor, I guess. It's its own string of conviction, this motor, this energy that's all in the background." (Adame, 2011, p327) Jones et al (2020) found that participants were likely to draw on their acute struggles of lived experience in their roles. Toikko (2016) identified how having lived experience of mental distress was the foundation to becoming an expert by experience. A parallel identity to that of survivor roots was that of disability roots, and this was the source of motivation to challenge and disrupt the system which is disabling (Cameron et al, 2019).

Exclusion/Stigma and Discrimination by services

This theme covered how lived experience researchers and providers felt they must hide their lived experience due to queries over competence and fitness to practice. (Adame, 2011; Newcomb et al, 2017). Service providers also chose who they listened to, and involvement could be tokenistic, recycling oppression lived experience researchers and providers experienced in contexts where they were service users (Cameron et al, 2019). Certain voices were excluded that were more chaotic and less professionalised (Jones et al, 2020). Cook et al (2015) also identify how the label of personality disorder is shaming and stigmatising, and diagnosistic practices operated in an inclandestine way excluding their involvement. Exclusion and alienation of those from minority ethnic backgrounds within these spaces was also discussed (Faulkner & Thompson, 2020). Hill et al (2021) also related service user and carer

involvement to a need to "break the glass ceiling" as staff were seen to hold the power and control the agenda.

Growth and Transformation

This theme encompassed experts by experience and co-researchers discussing effects of involvement leading to a metaphorical growth and transformation. "Seeing everybody still 'fighting for it'...the enthusiasm is more than ever... these are different people to the ones three years ago, I've been able to watch my teammates blossom!" (Hutchinson & Lovell, 2013, p646). Richards et al (2016) found the impact of these roles resulted in positively framed identities, facilitating recovery. It enabled individuals to have alternative, additional identities where the service user identity did not overshadow them. "So, it's not the most central thing anymore, that you're a mental health patient, but rather that you are a lot more as well." (Toikko, 2016, p303). Hill et al (2021, p 9) also found the theme of "The person you see now is not the person I was." This growth and transformation was related to the emergence of a professional identity, moving further away from the service user identity (Cooke et al, 2015).

Recovery model versus medical model

This theme found the recovery model was a facilitator in changing mental health identities to be seen as recovered. However, both the recovery model and medical model could both empower and disempower. Across the studies identities of lived experience researchers and providers were rooted in and influenced by these models. Despite models such as the social model of disability not locating the problem within the service user, the lens in which service providers worked "gets shifted back to medical model approach" (Cameron et al, 2019, p 1323) influencing identities to be seen as disordered. Richards et al (2016, p 10) found that those who drew on a "personal recovery" had more positively framed identities because it placed less emphasis on being "stuck". Adame (2011) identified an alternative discourse regarding the medical model, some service users found it helpful, and when the provider challenged the service users' alignment with the medical model, or of diagnosis, it was invalidating to how service users understood themselves and their experiences. Cooke et al (2015) felt the process of diagnosis was disempowering but became empowering once service users understood that the damage that came from diagnosis came from service providers. Hill et al (2021) also found that relations between service users and carers within involvement groups required a management of power dynamics.

Empathy of the self and others

This theme covered how the experience of being a lived experience researcher and provider led to an understanding of the self and others. Service user representatives found sharing stories of personal experiences turned them into common shared experiences of distress, enhancing empathy and reducing stigma. The PSW discussed the importance of being 'one of them' and able to 'get it.' (Simpson et al, 2018, p 665). Richards et al (2016) and Newcomb et al (2017) also found that personal experiences of distress enabled better understanding of those they worked with. Providing a social domain in which individuals shared their experiences as co-researchers meant they felt, understood, and better understood others (Hutchinson et al 2013; Jones et al 2020; Toikko, 2016; Hill et al, 2021). In relation to each other they also felt like they had similar experiences and a sense of "group survivorship." (Hill et al, 2021, p 6). Richards et al (2016, p 9) also identify a similar group identity through the idea of a shared "personhood" that supported understanding the self in relation to others' experiences and Cooke et al (2015, p 239), found it useful to connect and work with others who are similar like a "band of brothers." Adame (2011) found empathy of the self and others was impacted by overidentification, blocking a therapist's understanding of those they support. This meant that these roles sometimes supported or hindered understanding the self and others.

Motivation to integrate

Adame (2011) and Newcomb et al (2017) identify that lived experience providers were motivated to make a difference to others, due to their own lived experiences and wanted to prevent others experiencing the same injustices of the system. Positive experiences of services were motivators for becoming lived experience researchers or providers and modelling this experience in their own practice. Additionally, motivations to apply professional knowledge to better understand their own experiences was important (Richards et al, 2016). Cameron et al (2019) found a motivator to continue in the work as a service user representative was to purposely disrupt the power dynamics in these contexts. There was a need to move beyond the service user identity (Hutchinson & Lovell, 2013) and change their own narratives to more positively framed senses of self with a purpose in life. Faulkner & Thompson (2020) also identified that it was not simply enough to be working as lived experience researchers but to actively be integrating their lived experience into their work. Cooke et al (2015, p 239) also find that expert by experience roles were motivated in making use of past struggles "It almost comes worthwhile because you can almost see you're doing something with it."

Enablers and Empowerment

The lived experience researcher and provider role enabled moving beyond the service user identity (Hutchinson & Lovell, 2013). This was influenced by learning and combining new and existing skills (Simpson et al, 2018; Wilson et al, 2018; Cameron et al, 2019; Jones et al 2020; Toikko, 2016; Hill et al, 2021), and contexts situated in the recovery model, gave hope (Richards et al, 2016). Toikko (2016, p 303) found that through being an expert by experience led to an orientation towards the future. They were empowered after involvement (Jones et al, 2020) and through being listened to, heard and meaningfully involved (Cameron et al, 2019). It also gave meaning and purpose through "planting a seed" (Cooke et al, 2015, p 240). Hill et al (2021) also found that meeting challenges, resulted in self-belief by having control over decision-making. Activism, social change, politicised identities, and positive identities were developed because of these roles and were thought to facilitate recovery (Hill et al, 2021; Adame, 2011; Jones et al, 2020; Cameron et al, 2019; Cooke et al, 2015). However, some providers maintained there were fewer opportunities for those with drug user identities that were disempowered in their roles due to stigma and the permanence of a service user identity (Wilson et al, 2018).

Figure 2. A visual representation and summary of findings in the review
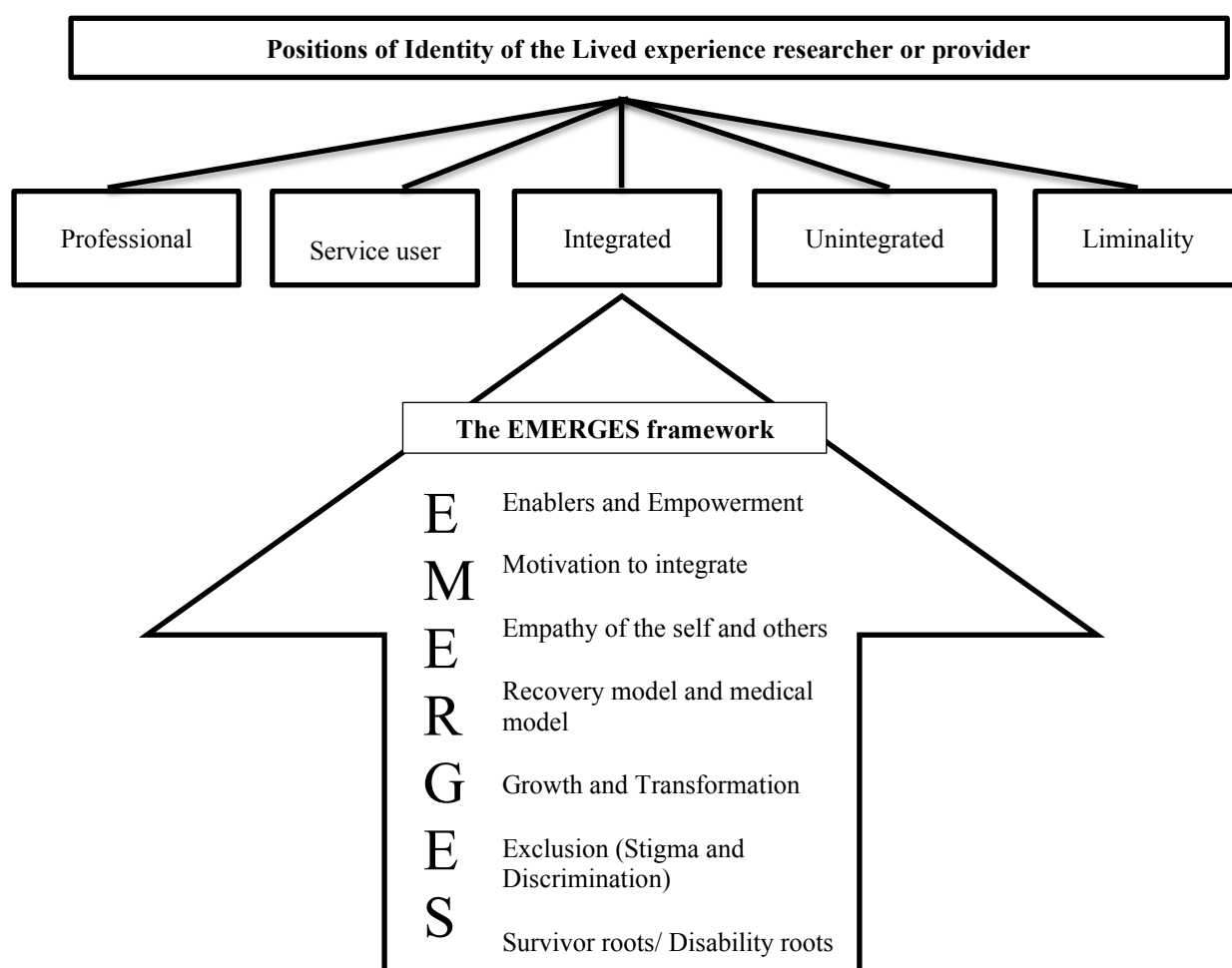
Stage 3: Checking the robustness of the synthesis: Reflections by Alison Bryant, Service user Advisor "I am in awe of the EMERGES framework and thoroughly relate to the themes and how my experience is integrated into those themes."

The robustness of the synthesis was checked by each member of the research team (VG, PF, LG, BG & CE) and researchers at McPin Foundation (RT & TM). AB, service user advisor uses the EMERGES framework to reflect on her lived experiences and evidences its utility as a reflective tool.

Survivor roots "*My long history of mental health presentations has defined me at every stage of my life. My experiences of services have been very varied, adding to the burden of my lived experience. Clinical psychology, and specifically mindfulness, has helped me to survive and be able to acknowledge that I have survived, and is now deeply meshed as part of my lived identity.*

Exclusion/Stigma and Discrimination: *I know holding my lived mental health experience and identity as being valuable to others (let alone myself) has been a hard road to travel. At times, my own perception of stigma, initiated feelings of exclusion, but also, I acknowledge that I have 'lost', through smoke and mirrors, some of my history and identity when I realised this was neither valued nor accepted, if not absolutely rejected. When the presence of imposter syndrome arises regarding my identity whilst working alongside academic or professional identities with no lived experience, I try to comfort myself that this is to be expected and to work towards reducing my feelings of exclusion.*

Growth and Transformation: *I and my family know how much my identity has been shaped by my involvement as a service user/provider. Both self-stigma and societal stigma have been a lens through which I have viewed my lived experience of mental health, this view having now been reframed in the context of my service user involvement. These experiences validate me and acknowledge my voice is heard. My knowledge sharing has empowered me so much, to the extent that sometimes I consciously listen to my voice that was once so subdued with a sense of surprise and ownership previously lacking.*

Recovery model versus medical model: *My clinical psychologist, in presenting me with the then novel concept that my experiences would be valued by others, was instrumental in me taking on the role of service user/provider. My initial involvement was at times bewildering,*

often surprising, but allowed my identity to develop bit by bit over time. My recovery from psychosis has been reinforced through my service user identity and involvement, but I am all too aware that there are periods when my mental health is less stable, and my service user involvement may be seen as less productive or useful. This presents me with an insurmountable hurdle to achieving full involvement unless, in the future, the "goal posts" are shifted with mental health adjustments to better support service user providers.

Empathy of the Self and others: *My service user involvement was a seed planted by my clinical psychologist that related to part of my identity which had always been at the forefront, and a heartfelt wish that others never had to go through the experiences in life and in managing mental health that I had done. Being able to demonstrate as a service user provider to those in training the reality of my lived experience helps shape them as practitioners. Sharing with other service users, identifying with them and offering support and solidarity through the challenges of shared lived identity is very empowering.*

Motivation: *For many years, my sense of self and identity had been eroded by the effort of constantly battling my mental health and despair at the impact on my quality of life and that of my family. My ability to be confident, to interact socially, my sense of self-esteem and sense of purpose had become lost in the struggle to become well. My most recent contact with services was a key factor in my recovery, and the incentive generated because of the therapeutic alliance with my clinical psychologist to help others was an overwhelming driver in my journey to recovery and new identity. My fractured self was pieced together in my pursuit of my newly formed service user identity.*

Enablers and Empowerment: *I had over time lost sight of skills or abilities I had held as part of other identities. Becoming a service user/provider allowed me to revisit those identities, to tease out what would sit alongside my mental health lived experience, to empower other service users, health professionals, trainees and ultimately myself. I now have a new perspective on my experiences gleaned from this new vantage point. I once had only a tiny seed of hope, now this has blossomed giving me a new sense of identity, purpose and direction.*"

Discussion

The review aimed to understand how the process of working as lived experience researchers and providers in mental health, education and research settings impacted identity and to develop a conceptual framework. The framework identifies five different positions of identity: Service user, Professional, Integrated, Unintegrated and Liminal identities and details themes of the EMERGES framework consisting of Enablers and Empowerment, Motivation, Empathy of the self and others, Recovery Model and Medical Model, Growth and transformation, Exclusion (Stigma and Discrimination) and Survivor roots. The EMERGES framework is a novel conception and has common themes of emotion and power running throughout, with some overlap between themes.

The Positions of Identity

The service user position is characterised as being disordered, limiting and considers the individual as the one with the problem. This is consistent with research in mental health settings, where illness identities are detrimental to hope and recovery, resulting in poorer mental health (Yanos, Roe, & Lysaker, 2010). The lived experience researcher or provider is expected to control their emotions and keep a distance from their illness, detracting from diversity and representativeness of service users who are chaotic or suffer with severe mental illnesses, influencing the type of identities within these roles (Beresford & Campbell, 1994). The service user has to switch between positions, for example, having to move between service user and expert by experience, where there are different levels of power, and control in decision making, requiring negotiation (Fox, 2016).

Professional identity was reinforced through training and labels used to describe them, giving them the skills and competences to work in their roles. This is consistent with, the Academy of Medical Royal Colleges (2020) that identify skills and knowledge to perform a professional role are key to developing a professional identity. Mayer & Mckenzie (2017) also find professional identities of experts by experience are influenced through interactions with experts by qualification and through performing these roles.

The Integrated identity was characterised by sharing lived experience both in research and clinical practice. Beames et al (2021) find the integration of lived experience in all stages of research supports meaningful research and outcomes. Arroll and Allen (2015) find self-disclosure results in greater therapeutic rapport and empathy. However, Bray, (2019) identifies the risks of self-disclosure and how it de-centres the service user. Alternatively, the peer support worker role requires them to work with patients through a shared experience of distress,

but they do not necessarily need to disclose as there is already a visibility of lived experience. Sharing of lived experience by professionals is likely to de-stigmatise the idea of mental illness (Corrigan & Watson, 2002; Thornicroft et al, 2016). Integrating lived experience in professional roles is related to being an authentic version of the self. Research into authenticity suggests that when we are authentic it is better for our health and wellbeing (Grijak, 2017), providing support for the benefits of lived experience roles.

The Unintegrated identity of the service user and professional identified how these identities were conflicting and could not be held simultaneously. Research suggests that experiential knowledge comes predominantly from the expert by experience, suggesting learning about experiential knowledge cannot come from mental health professionals. Additionally, professional knowledge is better assimilated when it comes from healthcare professionals as opposed to those with lived experiences (Hodge, 2005). This is explained by epistemic and hermeneutical injustice which poses limits on where knowledge is learned from (Fricker, 2007). Lived experience researchers and providers are also required to separate emotion and maintain professionalism in their roles. They must convey "affective intensity, while not spilling over into uncontrolled illness" (Naslund et al. 2019: 10). Researchers and professionals with lived experience are also impacted by stigma in the profession of lived experience that may determine whether they integrate lived experience in their research or clinical work.

The process of liminality described the identity of peer workers and researchers (Simpson et al, 2018; Faulkner & Thompson, 2020). Wu et al (2021) suggest that Liminal spaces negatively impact the mental health of individuals occupying this space. Warner and Gabe (2004) identify how mental health social workers find it difficult to work with mental health patients who occupy liminal spaces as they are difficult to understand and support. This can also translate to the way lived experience researchers and providers are understood and worked with in clinical practice and research, by colleagues. This knowledge can support service providers and colleagues to better understand those with liminal identities and enable better team working. It also identifies how these roles have an emotional burden on those performing them.

The EMERGES Framework

Outlined below are the seven core elements of the EMERGES Framework. Each element is considered in relation to the evidence base and how lived experience researchers or providers can be better understood and worked with in mental health, research and educational settings.

Survivor roots

This theme found becoming a lived experience researcher or provider was rooted in the history of being a survivor or service user of the mental/health system. The experience of trauma or iatrogenic harm from services can influence changes to identity. Through the process of having positive or negative experiences of services may be formative to self-identifying as a service user or survivor differently. Wallcraft et al (2003) identify the diversity of perspectives within and between service users and survivors but identify shared motivations to improve the mental health system. The intersectional influence of lived experience and professional aspects to the role (Crenshaw, 1989) means that this researcher or provider has more complex needs and requires greater support.

Exclusion/Stigma and Discrimination by services

Stigma and discrimination were shown to negatively impact disclosure of lived experience and health seeking behaviour and this is seen in wider contexts (Martin, 2010; Brown et al, 2010). The review team's own observations find service user involvement is typically made up of white service users and is unrepresentative of the population which may be symptomatic of exclusion in the mental health system. There are also them and us divisions between lived experience researchers and providers and those they work with. For example, knowledge of stigmatised diagnostic labels, such as personality disorder, affects how experts by qualification perceive and work with them (Clarke et al, 2015). There are also divisions between different lived experience researchers and providers, for example, experts by experience and mental health professionals with lived experience, meaning different lived experience researchers and providers do not belong to the same identity.

Growth and transformation

The review found a consistent theme of growth and transformation. This links to a broader body of evidence within literature on how service users or survivors of mental or physical disability experience post traumatic growth (Tedeschi & Calhoun, 1996). Theoretically driven research metaphorically likens the effects of service user involvement to

growth and transformation (Tse et al, 2012) and research finds the expert by experience role results in transformative effects (McCoy & Aronoff, 1994; Onken & Slaten, 2000). Some lived experience researchers and providers also have a romanticised perspective and find transformative effects in identity following the experience of psychosis (Conneely et al, 2020). Schneider et al (2019) find non-white people and those with serious forms of distress are more likely to experience greater post-traumatic growth, suggesting the trajectory of growth and transformation of lived experience researchers and providers may be variable.

Recovery model and medical model

The wider literature identified the recovery model was more likely to lead to feeling more hopeful and move individuals further from the service user identity (Walker, Crowe & Caputi, 2010). The recovery model arguably has a negative side that promotes a certain journey for service users, modelling ideas about competence, expertise and health outcomes that reduce the ideal service user to someone that is recovered (Harper & Speed, 2014). This limits the type of individual in lived experience researcher and provider roles, reducing representativeness and authenticity of service users. The recovery model ironically detracts from the service user identity. In contrast, the medical model reinforces the service user identity, positioning the service user as in need of help, as ill or disordered (Beresford, 2010). The context and models in which individuals are situated in can influence the way individuals conceptualise their own experiences. This aligns with social constructionism epistemology (Berger & Luckmann, 1991). The recovery model, medical model and social disability model are pervasive in the sector and explain findings in the review and how lived experience researchers and providers' differently construct their identities based on the models they identify with.

Empathy of the self and others

This theme found how sharing experiences within a social domain were used to connect with and understand others. The social identity of the lived experience researcher and provider role provided a sense of belonging to an in-group where we share similar values, beliefs, and experiences, supporting the formation of a social identity (Tajfel & Turner, 1979). The historical exclusion of this group of people in society means the role enables them to have a sense of belonging. Hawkins (1999) suggests a desire to tell others about our own experiences becomes a desire to help others and this is a motivating factor in integrating lived experience. The process of lived experience researcher and provider identities may mean they better understand the people they research or work with and make them better person-centred

practitioners (Rogers et al, 1959). However, issues relating to transference and countertransference can negatively impact understanding others through the projection of one's own lived experiences.

Motivation to integrate

This review identifies the idea of motivation to integrate lived experience and professional identities and hold them simultaneously. This motivation aligns with wider mental health contexts, for example, the division of Clinical psychology (DCP, 2020) released guidance on how trainee psychologists can integrate their lived experience into their work and training (DCP, 2020). This suggests the lived experience researcher or provider and mental health training are in alignment regarding motivations to integrate lived experience. This is likely influenced by changes in policy (DOH, 1999; 2000; 2001) and the service user movement (Chambers & Hickey, 2012).

Empowerment and Enablers

The review found the idea of empowerment through lived experience researcher and provider work and this may occur through a social justice motivation (Huse, 2020). Through lived experience researcher and provider roles that are politically motivated, formed of activists and advocates means they are moving away from individual motivations to make a difference to a collective motivation to make a difference for others like themselves. This may be governed by social identities (Tajfel & Turner, 1979). Belonging to a social identity is likely to result in the health and wellbeing of members in the group, strengthening the group and empowering it and advocating for it. This can be explained through the social cure phenomenon in social identities (Jetten, Haslam & Haslam, 2011). Further to this, reaction against out-groups provides a motivation to disrupt and challenge other social identities such as Psychiatry or Psychology.

The EMERGES framework and links to other frameworks

The EMERGES framework conceptualises the identities of lived experience researchers and providers and builds on previous frameworks in other contexts, offering a novel way to understand identity. There are parallels with findings from the CHIME framework, which is made up of themes of Connectedness, Hope, Identity, Meaning, Empowerment (Leamy et al, 2011). Although the CHIME framework is critiqued as being overly optimistic and positive, and other researchers argue it does not account for difficulties that service users

experience, advocating for an addition of D to the CHIME framework representing difficulties (Stuart, Tansey & Quale, 2016). In contrast, the EMERGES framework explicitly highlights the exclusion lived experience researchers and providers experience which is undermined by the retrospective addition of the D in CHIME-D framework. There is also overlap with Emery's literature review (2015) of service user involvement, finding themes of empowerment, recovery and identity, giving validity to this review. Ng et al (2021) find in their conceptual review of psychosis and growth and transformation the acronym of PROSPER, Personal identity and strength, Receiving support, Opportunities and possibilities, Strategies for coping, Perspective shift, Emotional experience, and Relationships. The EMERGES framework encompasses similar themes to these frameworks but specific to lived experience researchers and provider identities, offering a novel and accessible way to understand them.

Strengths of the review and framework

The review identifies the novel EMERGES framework which can be used as a reflective tool and has practical applications both within research and clinical settings with the heterogeneous population of lived experience researchers and providers. The framework was co-created with a multi-disciplinary team, including lived experience researchers and providers, at every level within the review, adding to the robustness and validity of the findings and additionally, peer reviewed by researchers at McPin Foundation. Quality appraisal was also carried out independently by three different PhD Psychology students, with different expertise in lived experience and research methods. The methodologies within the studies were informed by a wide range of philosophical approaches that contributed to this synthesis. The research questions and aims of the studies differed slightly and so their synthesis may not represent each individual study's findings cohesively, but instead the review identifies common themes across all. These are informed through a range of perspectives and philosophical underpinnings that supports the robustness of the synthesis. The framework has also been reviewed by researchers in other settings who suggest its value and application in mental health settings more generally, evidencing its versatility and wide-reaching impact.

Limitations of the review

It is acknowledged the review did not explore the grey literature, or literature on ethnicity, LGBT and gender identity and this may have cast further insight into identity formation, but this was not a focus of the review. Most studies within this review failed to discuss the lack of diversity within lived experience researcher and provider roles. Only one

paper (Faulkner & Thompson, 2020) addresses this issue explicitly, but this study's sample size was mostly white, meaning it is difficult to draw meaning from such conclusions. The reviewed studies highlight how the field is limited to lived experience researchers and providers who can communicate their experiences and manage their emotions with competence and professionalism. This excludes those with severe mental or physical disabilities and those with learning disabilities. The carer voice and their work as experts by experience or providers is also largely missing from the studies included within this review, only, Hill et al, (2021) included carers within their study. A proportion of the studies within the review are complex and academic in nature and may be difficult for lay people to understand, suggesting that the people who can benefit from the research may not due to lack of accessibility. This meant that the review team were mindful of those who would benefit from reading the review and were motivated in communicating this in an accessible way. It is also acknowledged the field of lived experience work is referred to in a diverse set of ways nationally and internationally and so the search strategy may not have captured all research in the area. There is also a lack of literature exploring the effects of lived experience researchers and provider roles on identity, evidenced through only thirteen papers in this review, and so there is a recommendation for adding to the evidence base.

Conclusion

This review elucidates the identities of lived experience researchers and providers in mental health, education, and research and gives greater clarity to these identities that are sometimes not understood by themselves or the people they work with. The EMERGES framework can be used as a reflective tool to better understand those is these roles and support effective team working. The review highlights how lived experience researcher and provider roles are performed by individuals with certain characteristics such as those who are professional, articulate and those who can separate and integrate, when appropriate, their lived experiences. However, people who do not have these characteristics and people from ethnic minority backgrounds, in addition to those with severe and enduring chronic mental, physical and learning disabilities, are often excluded from these roles. Furthermore, it is evident that carer involvement in these roles is also underrepresented. This clearly limits the identities of those in these roles. Through the integration of more underserved communities in lived experience roles can lead to a depth of experience that can be drawn upon, leading to growth and transformation in the sector. However, the integration of lived experience within these contexts is limited, due to stigma and discrimination, limiting self-disclosure and health-

seeking behaviours due to the professionalisation of these roles. Therefore, those working with lived experience researchers and providers need to be aware of their support needs which can be guided by the practical application of the EMERGES framework. There is also a need to integrate lived experience to be authentic and also a motivation to promote social justice in the mental health system. Through the process of sharing lived experiences supports others to listen and learn from them and supports greater empathy of one's own distress and that of others.

Through the process of performing these roles and through moving through the stages of the EMERGES framework leads to identity development. In some cases, the stigma of mental illness, and/or disability permanently marks the identity of lived experience researchers and providers, affecting their prospects and the lens through which they are viewed. However, the general trend among the literature highlights how lived experience researcher and provider roles moves them beyond the service user identity. This consequently transforms those with stigmatised identities to enabling and empowered identities, facilitating recovery.

Declarations

There are no conflicts of interest or declarations to make

Data availability within the article or its supplementary materials

The authors confirm that the data supporting the findings of this study are available within the article [and/or] its supplementary materials. These can be shared upon request.

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