

Service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training

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Thesis abstract

This study explores the experiences and personal effects of service user (SU) involvement in clinical psychology training. A critical realist stance was adopted throughout the research process.

Extant literature has predominantly focused on evaluating and optimising SU involvement for the benefit of clinical psychology trainees. Only recently has research started to consider the effects involvement may have on SUs. The research exploring SUs' experiences in clinical psychology training has derived samples from singular training programmes. Exploring SUs' experiences from multiple programmes seemed the logical next step. The deductive application of psychological theory allowed further exploration into power, recovery, identity and group development (concepts highlighted as important in the SU involvement literature).

Purposive sampling was utilised, with advertisements disseminated via course staff who oversee SU involvement. Fourteen SU representatives, from eight different courses were recruited (with two also identifying as carers). Each participant took part in either a face-to-face or telephone semi-structured interview which was audio recorded and transcribed by the researcher. A deductive thematic analysis was used to analyse the data.

Five themes were identified, some with subthemes: Environment determines sense of safety (subthemes: Supportive relationships, Group dynamics); Meeting challenges; Sense of purpose, worth and value (subthemes: Feeling listened to and valued, A positive way to feed back into the system); The person you see now is not the person I was (subthemes: A game changer for personal growth and development, Relating to difficulties in a different way, Reengaging with skills that I thought had gone); and Wanting to break the glass ceiling. Findings are considered and discussed in relation to theories of social identity, power, group development and mental health recovery.

Identified benefits for SUs included a positive change in self-perception, including re-engaging with lost skills. Findings suggest involvement can offer an opportunity to further develop recovery. However, there were reported difficulties in joining a new SU group including group dynamics and power imbalances.

Findings also suggest that there is a glass ceiling to involvement which SUs have a desire to break.

The findings suggest it is important that the environment in clinical psychology training fosters psychological safety for SUs, via positive and supportive relationships with trainees and staff, in which SUs are treated as equal colleagues and financially reimbursed as such. Additionally, the intricacies and nuances of managing and sharing power need to be explored to enable SUs to feel valued and reap benefits from involvement, including developing a positive sense of identity. There are also implications for professionals in mental health services who should look to share theoretical knowledge with SUs who reportedly found that having access to psychological theory via their involvement was enlightening in better understanding their difficulties.

A limitation is only two participants identified as carers (and they also identified as SUs) therefore carers experiences are under-represented. The research also failed in attempts to recruit SUs who were no longer involved, and thus whose experiences might differ. Future research should focus on these areas.

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Statement of contribution

The main author was responsible for the following aspects of the research: project design, applying for ethical approval, writing the review of the literature, recruiting participants, data collection, data transcription, data analysis and writing the research report.

Dr Anna Tickle aided with study design, recruitment of participants and reviewed and offered comments on the main author's coding and theme development. She also provided research supervision and offered comments on drafts of the write up.

Dr Danielle De Boos aided with recruitment of participants and offered research supervision and comments on the drafts of the write up.

Tara Shennan offered research supervision from a service user perspective and aided with study design – in particular, the development of the semi-structured interview protocol.

The following offered support with recruitment by disseminating study information to service user representatives on their respective programmes: Laura Lea, Sharon Galliford, Dr Nick Hutchinson, Dr Annette Schlosser, Dr Tracey Smith, Dr Beth Greenhill, Dr Matthew Knight, Dr Kate Theodore, Dr James Lea, Dr Emma Munks and Dr Jo Heyes.

The systematic literature review was completed by Adam Hill and revised by Dr Anna Tickle for submission to the Child and Adolescent Mental Health journal. The small-scale research project was completed by Adam Hill on a clinical placement.

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SYSTEMATIC REVIEW

Transition from Child and adolescent (CAMHS) to adult mental health services (AMHS): A metasynthesis of parental and professional perspectives

Abstract

Background:

Young people transitioning between child and adolescent (CAMHS) and adult mental health services (AMHS).

Objectives:

To develop a more comprehensive understanding of the transition experience between CAMHS and AMHS by systematically exploring the evidence regarding professionals' and parents/carers' perspectives relating to their experiences of adolescents making the transition.

Data sources:

A systematic search in July 2018 of Medline, PsycINFO and CINAHL. Google Scholar was also searched, as well as the reviewing of reference lists of relevant articles.

Study selection:

Empirical qualitative research in peer reviewed journals with a primary focus on investigating experiences of parents/carers and/or mental health professionals in relation to adolescents making the CAMHS-AMHS transition, with independently extractable data.

Data extraction:

Data was extracted from each full-text paper by the primary reviewer using a data extraction form. An expanded version of the Critical Appraisal Skills Programme tool was used to appraise the quality of the included studies, and their results were synthesised using metaethnography.

Results:

14 studies of variable quality were identified. Four main third-order constructs pertinent to transition were developed through synthesis: 1) Service cultures; 2) Service resources and gaps; 3) Working relationships between the services; 4) Leaving secure relations and developing new relationships.

Conclusions:

Professionals and parents experience adolescents' CAMHS-AMHS transition as being turbulent with many barriers. Due to cultural differences, it would be beneficial to have one service for both adults and children. Greater focus needs to be given to managing relationship endings in CAMHS and the development of new relationships in AMHS. Parents and professionals desire better preparation for transition, more joint working and better CAMHS-AMHS communication. Many of these difficulties could be aided by increasing CAMHS-AMHS cooperation. AMHS resource gaps exist for those with neurodevelopmental conditions, which should be an area for future service development and research.

Key words:

Transition, adolescent, young people, mental health, health services

Introduction

Research suggests that most mental health difficulties begin in adolescence (Jones, 2013). It is suggested that the further into adolescence a difficulty begins, the more likely it will continue into adulthood (Kim-Cohen et al., 2003). Therefore, a significant number of adolescents who are seeking support from Child and Adolescent Mental Health Services (CAMHS) for mental health difficulties are likely to require transition to Adult Mental Health Services (AMHS).

CAMHS-AMHS transition occurs between ages 16 and 18, varying across cultures and services. This time period coincides with psychological,

physiological and social changes (Singh, 2009) which can be a difficult phase for adolescents. This difficult phase is exacerbated for those who have the added pressures of contending with mental health issues and navigating the move from CAMHS to AMHS. This period can also invoke uncertainty and apprehension for families (Jivanjee, Kruzich, & Gordon, 2009). To minimise distress to the young person and their family, the transition therefore needs to be smooth and well managed. In attempts to aid with this, National Institute for Health and Care Excellence (NICE) guidance has been developed in the UK which stresses the young person be given the option to be involved in all aspects of the transition, and advocates for the transition to occur when the young person is developmentally stable (NICE, 2016). However, for various reasons transition can often be disruptive; McGorry (2007) argues that, “the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest” (p. S53).

CAMHS-AMHS transition might be considered in the context of attachment theory (Bowlby, 1982). Attachment theory emphasises establishment of a secure base with a primary attachment figure who is then available consistently over time. Within a mental health service this equates to continuity of care by a consistent relationship being built between staff in a service and the service user (Bucci, Roberts, Danquah, & Berry, 2015). Moreover, Adshead (1998) suggests that patients may see clinicians as attachment figures. Transition means that relationships with staff in one service will end, meaning losing a secure base which is no longer consistently available. This marks the transition between services as a significant event in the adolescent’s life. Attachment theory suggests stability and continuity of care throughout transition should be promoted. However, a fragmented system (Jivanjee & Kruzich, 2011) and a general lack of adult services (Paul, Street, Wheeler, & Singh, 2015) are barriers to promoting stability and continuity of care during transition. Bucci et al. (2015) suggest that to promote stability, transitions should be planned for in advance and that services should acknowledge the impact and problems transition can bring for the patient. In the case of adolescents this impact will likely extend to parents/carers. It is probable

that clinicians are aware of the benefits of smooth transitions, yet little is known about their views regarding why these are so hard to achieve.

Research on CAMHS-AMHS transition has been drawn together in several literature reviews. A narrative review by Reale and Bonati (2015) concluded transition to be problematic, with the reasons varying across settings and countries (i.e., differences in professional education). A difference in treatment approach between CAMHS and AMHS was also highlighted. The authors recommend a need for governments, services, clinicians and parents to work together to achieve a seamless transition. In addition, a review by Paul et al. (2015) identified significant policy-practice gaps such as commissioning issues, a lack of leadership and not prioritising transition-aged adolescents. In both reviews, transition knowledge may have been expanded by using a more systematic approach to data identification and analysis such as metasynthesis. This may have enabled movement beyond findings of individual studies by developing new meaning.

A systematic review focusing on CAMHS and AMHS care philosophies and the influence on transitions was conducted by Mulvale et al. (2016). The authors reported that differences in care philosophies were found across the literature. They recommended a need for CAMHS and AMHS to better understand each other and how their differences can influence the transition experience for adolescents and their families. The authors used a deductive approach to data analysis by using pre-conceived ideas about care philosophies to analyse the data. This may have meant that other broader aspects of transition experience were not captured. An inclusion criterion was papers focusing on care philosophy, excluding papers focused on other aspects of transition experience. The authors also did not draw out differences between parental and professional experiences in their analysis. Exploring each group's views may have been useful to tease out similarities or differences in experiences.

Recently, a systematic review by Broad, Sandhu, Subderji and Charach (2017) aimed to understand adolescents' CAMHS-AMHS transition experience by conducting a thematic synthesis of the literature. Adolescents found the

transition difficult at a time when they were also undergoing other transitions and desired more involvement, joint working and flexibility in transition timing.

Aim and rationale

The primary aim of the current review is to develop a more comprehensive understanding of CAMHS-AMHS transition experience by systematically exploring the evidence regarding professionals' and parents/carers' perspectives relating to their experiences of adolescents making the transition. In addition, the review aims to inform future research by systematically identifying existing research and appraising its quality, enabling identification of any under-researched areas and methodological issues that can be improved upon in future research.

Transition is a complex process which has led to some reviews taking a more specific focus (Mulvale et al., 2016). The present review aims to broadly consider transition experience, remaining open to what professionals and parents identify as important issues in transition rather than privileging aspects selected by the reviewers. Findings will be considered alongside current literature and policy to identify ways forward clinically and in research.

Methodology

The review was approached from a critical realist epistemological position. This assumes that an external reality exists whilst also accommodating personal and interpersonal subjective realities (Rana & Chad, 2006). Therefore, it is acknowledged that objective factors (in this instance transition) are interpreted subjectively by research participants, the authors of included studies, and the reviewers.

The primary author is a Trainee Clinical Psychologist, whilst the secondary authors are both Clinical Psychologists working in CAMHS and AMHS respectively. All authors have an interest and professional experience in the transition process, qualitative research and metasynthesis.

Inclusion criteria

Studies were included if they:

- Reported empirical research using qualitative methodology
- Were published in peer-reviewed journals
- Had a primary focus on investigating experiences of parents/carers and/or mental health professionals in relation to adolescents transitioning from community CAMHS to AMHS settings (both uni-disciplinary and multi-disciplinary services), whether generally or in relation to specific aspects of transition
- Included data from each group (professionals, carers/parents) that was independently extractable

Exclusion criteria

Studies were excluded if they:

- Were not published in English
- Used only quantitative methodology
- Only explored transition between child and adult physical health services

Searching

A systematic search was conducted on Medline, PsycINFO and CINAHL databases on 6th July 2018. Google Scholar was also searched. The search terms used are shown in Table 1.

Table 1.

Search terms used

Database	Search terms
Medline	1) qualitative OR lived experience OR ethnography OR phenomenology OR biography OR interview OR personal narrative OR autobiography OR grounded theory OR thematic analysis OR focus group OR dairies OR experience OR perspective OR theme OR (MH "Qualitative Research"); 2) transition* OR transfer OR moving OR progressing OR (MH "Transition to Adult Care") OR (MH "Transitional Care") OR (MH "Health Transition"); 3) mental health service* OR camhs OR mental health care OR (MH "Mental Health Services") OR (MH "Community Mental Health Services"); 4) young people OR youth OR adolescents OR young adults OR teenagers OR children. Searches 1, 2, 3 and 4 were combined using AND
PsycINFO	1) qualitative OR lived experience OR ethnography OR phenomenology OR biography OR interview OR personal narrative OR autobiography OR grounded theory OR thematic analysis OR focus group OR dairies OR experience OR perspective OR theme OR (DE "Qualitative Research"); 2) transition* OR transfer OR moving OR progressing 3) mental health service* OR camhs OR mental health care OR (DE "Mental Health Services") OR (DE "Community Mental Health Services"); 4) young people OR youth OR adolescents OR young adults OR teenagers OR children. Searches 1, 2, 3 and 4 were combined using AND
CINAHL	1) qualitative OR lived experience OR ethnography OR phenomenology OR biography OR interview OR personal narrative OR autobiography OR grounded theory OR thematic analysis OR focus group OR dairies OR experience OR perspective OR theme OR (MH "Qualitative Studies") 2) transition* OR transfer OR moving OR progressing OR (MH "Health Transition") OR (MH "Transitional Care") 3) mental health service* OR camhs OR mental health care OR (MH "Mental Health Services") OR (MH "Community Mental Health Services") 4) young people OR youth OR adolescents OR young adults OR teenagers OR children. Searches 1, 2, 3 and 4 were combined using AND

Equivalent searches were used in each database with adjustments made to use synonyms specific to that database.

Results were imported to Endnote and duplicates removed. Papers were screened against inclusion/exclusion criteria at title/abstract level. Full-texts were reviewed when they appeared to meet criteria or if there was uncertainty from initial screening. Relevant articles' reference lists were reviewed to identify further papers.

Data Extraction

Data was extracted from each full-text paper by the primary reviewer using a data extraction form. The forms were reviewed by the other reviewers. Discrepancies were resolved via consensus.

Critical appraisal

Quality appraisal in literature reviews is deemed vital (Dixon-Woods, Booth, & Sutton, 2007). To maximise evidence regarding quality, an expanded version of the Critical Appraisal Skills Programme (2018) tool was used to appraise the quality of studies included within the review. Each article was appraised against 18 quality criteria. The following scores were assigned: zero if not met, one if unclear and two where definitely met. Whilst there is an acknowledgement that some studies scored worse than others, the current research acknowledges the potential for all studies to contribute towards the findings, regardless of quality score (Sandelowski, Docherty, & Emden, 1997).

Synthesis of findings

Metasynthesis is a rigorous method which aims to interpret and synthesise research findings to construct greater meaning and deeper understanding beyond individual studies (Erwin, Brotherson, & Summers, 2011), as well as identifying research gaps (Major & Savin-Baden, 2010).

In meta-ethnography (a form of metasynthesis), reciprocal translation (Noblit & Hare, 1988) is used to identify common themes, whereby key concepts across studies are identified. This can be conducted using a concept from a study or by developing a new construct to highlight similar findings. Contradictory accounts are also sought, enabling contrasts between findings to be highlighted. Based on the identified concepts, a line of argument synthesis is developed (Noblit & Hare, 1988).

The process of metasynthesis varies (Erwin et al., 2011). Typically, first and second-order constructs are linked together to develop new third-order constructs. First-order constructs are contextual, consisting of original participant quotes, whilst second-order constructs are themes which have been developed by the original researchers (Erwin et al., 2011). Third-order constructs derive from the metasynthesis and consist of new and common themes.

In the present review, both first-order and second-order constructs from the studies were reviewed. These were then synthesised into third-order constructs, developed by the reviewers using reciprocal and refutational synthesis. Reviewing first and second-order constructs can be useful when first-order constructs do not obviously support the researcher's suggested theme but may support another third-order construct (Bailie & Tickle, 2015).

Results

Systematic search

Search details are presented in an adapted Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) in Figure 1.

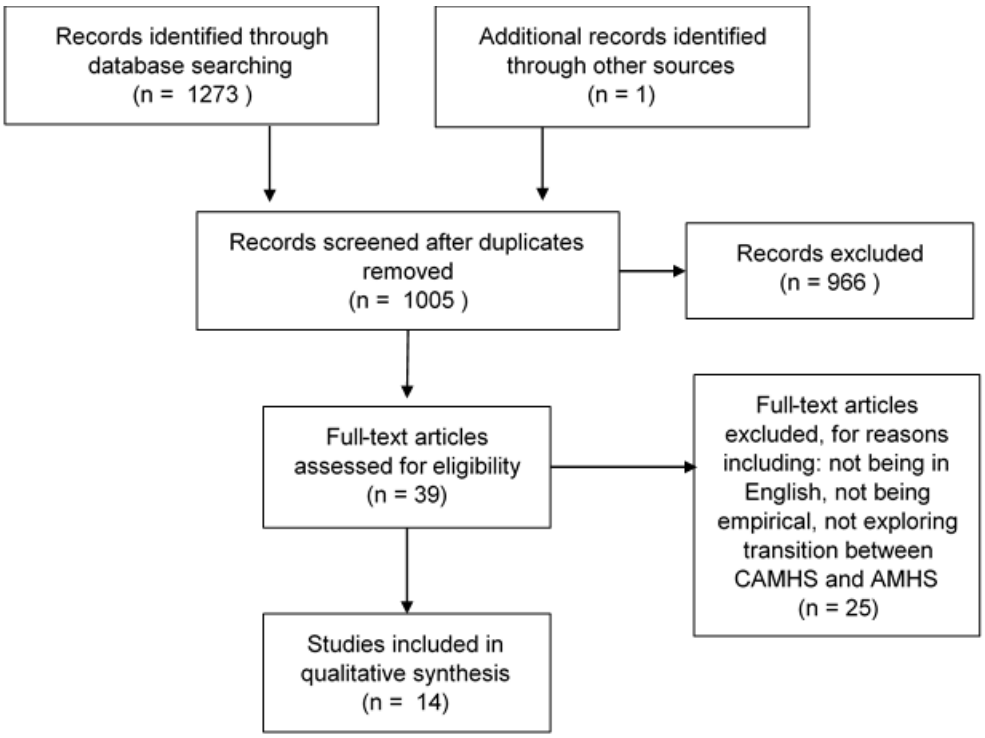


Figure 1. Flowchart for systematic review

After duplicates were removed, 1005 titles/abstracts were checked against inclusion and exclusion criteria. 39 full-text articles underwent more rigorous checking. Uncertainty was resolved by another author also reviewing papers and consensus was reached. Fourteen studies were included in the review. The general characteristics of each study are described in Table 2, along with the number that will be used to refer to each study throughout.

Table 2.

General study characteristics

Study	Authors (year), location	Aims	Qualitative data collection method	Sample	Data analysis method	Key findings
1	Belling et al. (2014), UK	To investigate the organisational factors that facilitate or impede the effective transition of young people from CAMHS to AMHS from the perspective of health professionals and representatives of related voluntary organisations.	Semi-structured interviews (SSI)	34 health and social care professionals from four NHS trusts, representing CAMHS, AMHS and voluntary sector. Comprising 8 nurses, 6 psychiatrists, 2 psychologists, 7 social workers, 7 managers and 4 other.	Structured thematic approach	Lack of understanding of services and structures, restrictive eligibility criteria and lack of resources can impact negatively on the transition between CAMHS and AMHS, disrupt continuity of care, and create inequalities in service access and provision.
2	Dunn (2017), UK	To co-devise, with service users and practitioners, a CAMHS Transition Preparation Programme (TPP) deliverable in routine NHS settings	Creative participatory workshops in three stages. Various activities (written/drawing) and discussion Questionnaires	17 young people (12 females, 4 males, 1 gender fluid) aged 16-22. 30 CAMHS and AMHS staff (including psychiatrists, psychologists, OT's, SPA staff, team managers) 7 parents.	Ongoing consensus and independent evaluation. Planned thematic analysis of parental questionnaires did not occur due to time restraints.	A CAMHS TPP should be engaging, relevant and deliverable in routine mental health settings. Young people leaving CAMHS desire help to build confidence, identify sources of support and improve knowledge to enable them to take responsibility for their own care.

Table 2. (Continued)

Study	Authors (year), location	Aims	Qualitative data collection method	Sample	Data analysis method	Key findings
3	Hovish, Weaver, Islam, Paul and Singh (2012), UK	To discuss young people's CAMHS to AMHS transition experiences, those of their parents and the perspectives of mental health professionals.	SSI	11 young people (6 males, 5 females) with range of diagnoses. 6 parents. 3 CAMHS key-workers. 6 AMHS key-workers.	Thematic analysis (TA)	Transfer planning meetings and good information transfer important to all. CAMHS and AMHS operate within different practical, legal and theoretical contexts. Parents worry, and clinicians frustrated about lack of communication and continuity of care between services Parents reported unwanted reduced involvement after transfer to AHMS
4	Kaehne (2011), UK	To investigate how mental health professionals organise transition for young people with intellectual disabilities, what they consider the main gaps in service provision, and what they think the main obstacles to smooth transitions are.	SSI	8 professionals from 3 local authorities in Wales consisting of: 1 manager of residential unit for adolescents with MH problems CAMHS: 1 team manager 2 psychiatrists 1 clinical psychologist AMHS: 1 team manager 1 clinical psychologist 1 psychiatrist	TA	Mental health teams are rarely part of transition planning frameworks. The main organisational problems of transition relate to different eligibility criteria between CAMHS and AMHS, different service models between children and adult services, and lack of knowledge transfer infrastructure.

Table 2. (Continued)

Study	Authors (year), location	Aims	Qualitative data collection method	Sample	Data analysis method	Key findings
5	Kuhlthau, Warfield, Hurson, Delahaye and Crossman (2015), US and Canada	What are the current strategies or interventions taking place in ASD-specific paediatric settings to facilitate successful transition from paediatric to adult health care for youth with ASD? What strategies or interventions are needed or would be most helpful in facilitating the transition from paediatric to adult health care for youth with ASD?	SSI	19 healthcare professionals from a network of paediatric ASD treatment centres consisting of: 5 physicians 5 psychologists 7 social workers/care coordinators 2 registered nurses	Three stage framework approach	Family educational seminars and care binders are suggested implementations. System-based interventions such as increased training of adult providers suggested.
6	Lindgren, Sköderberg and Skär (2013), Sweden	To describe professionals' experiences and views of the transition process from Child and Adolescent Psychiatry (CAP) to General Adult Psychiatry (GAP)	Three focus groups with professionals from CAP, three focus groups with professionals from GAP	12 professionals from CAP, 11 professionals from GAP made up of: 6 registered nurses 6 assistant nurses 1 psychotherapist 1 psychiatrist 2 heads of unit 1 occupational therapist 1 psychologist 3 welfare officers 2 social educators	Deductive content analysis	Young adults need sufficient information and a possibility to prepare before the transfer. Professionals should focus on providing information, cooperating, and transition planning. Parallel working with an individual approach facilitates transition from CAP to GenP.

Table 2. (Continued)

Study	Authors (year), location	Aims	Qualitative data collection method	Sample	Data analysis method	Key findings
7	Lindgren, Sköderberg and Skär (2014), Sweden	To explore expectations and experiences of transition from CAP to GenP as narrated by young adults and relatives.	Individual interviews	From 2 outpatient units when it was time to terminate care in CAP and referral to GenP 3 young adults (2 females, 1 male) 6 relatives (4 mothers, 1 father, 1 keyworker)	Grounded theory	Person-centred transition planning recommended. Professionals should plan the transition through cooperation between CAP and GenP with the young adults and relatives participating.
8	Lindgren, Sköderberg and Skär (2016), Sweden	To explore relatives' experiences of parenting a young adult with mental illness who is in transition to adulthood.	Individual interviews	10 relatives (2 fathers, 8 mothers) of young adults aged 18-25 who had experience of both CAP and GenP	Grounded theory	Important to support relatives in reaching a balance between taking responsibility and letting go during their young adult's transition. By supporting relatives and considering them as resources, relatives' feelings of powerlessness can be reduced.

Table 2. (Continued)

Study	Authors (year), location	Aims	Qualitative data collection method	Sample	Data analysis method	Key findings
9	McLaren et al. (2013), UK	To explore the organisational cultures, structures, processes and resources which could influence the transition from CAMHS to AMHS; To identify specific organisational factors which constitute barriers and facilitators to transition and continuity of care; To make recommendations for changes in services which could improve young people and carers' experiences of transition and experienced continuity of care.	SSI	34 health and social care professionals in NHS trusts and 4 voluntary sector staff Comprising nurses, social workers, psychiatrists, psychologists, service managers and other 16 CAMHS staff 11 AMHS staff 3 CAMHS and AMHS (service managers) 4 voluntary sector staff	Structured thematic approach	A cultural divide between CAMHS and AMHS, marked by different beliefs, attitudes, understanding and some negative misperceptions. Some working practices could constitute barriers to effective transition, relational, informational and cross boundary continuity of care. Some positive approaches to collaborative working between services and external agencies which can support transition and continuity.
10	McNamara et al. (2017), UK	What social identity changes are implicated in mental healthcare transition? How do social identity processes influence transition experience and subsequent service engagement?	SSI	11 young people, 8 completed transition, 2 still undergoing transfer, 1 had refused referral to AMHS. 5 of their parents 11 CAMHS lead clinicians 8 AMHS lead clinicians	Theoretically guided TA	Social Identity Model of Identity Change can be usefully applied to understand the social psychological consequences of the mental healthcare transition process. It offers additional insights into some of the barriers and enablers to successful transition experienced by young people and their parents.

Table 2. (Continued)

Study	Authors (year), location	Aims	Qualitative data collection method	Sample	Data analysis method	Key findings
11	Reale, Frassica, Gollner and Bonati (2015), Italy	To describe the experiences of parents and clinicians in relation to the transition from child and adolescent neuropsychiatric services (CANPS) to adult services for people with attention deficit hyperactivity disorder (ADHD) in Italy	Questionnaire	24 parents of ADHD patients aged 18 or older identified via a mailing list 27 child psychiatrists from CANPS	Not reported	Defined protocols, adequate allocation of resources, appropriate training initiatives and involvement of patients and families should be improved to better manage the transition process and to avoid the healthcare gap.
12	Richards and Vostanis (2004), UK	To establish themes of mental health service needs for young people aged 16 – 19 years, as perceived by professionals from all agencies involved in their care	SSI	18 managers and 21 practitioners (including psychiatry, nursing, psychology) from 22 statutory and five non-statutory services (AMHS, CAMHS, specialist MHS, LD services, Educational Psychology social services, health authority, youth offending team, non-statutory sector).	Thematic content analysis based on grounded theory	High motivation to improve services for one of the most neglected age groups. Interprofessional protocols and transfer arrangements are needed. For more severe psychiatric disorders there should be planned transfers to adult mental services, and co-ordination of all necessary agencies, involving three-way meetings and comprehensive handover. Joint working for a limited time might be helpful. Age cut-offs need to be consistent across all agencies. Joint training programmes will help frontline staff learn from each other's approach to mental health assessment and treatment.

Table 2. (Continued)

Study	Authors (year), location	Aims	Qualitative data collection method	Sample	Data analysis method	Key findings
13	Singh et al. (2010), UK	Part of the wider TRACK study. The aim of interest was to explore the views of service users, carers and mental health professionals on the process of transition experience from a subsample of service users	SSI	11 service users at transition age or above 6 parents 3 CAMHS clinicians 6 AMHS clinicians	Constant comparative method within framework approach	Current transitional care inadequate. Early and substantial service improvement needed, some of which can occur without new resources and by simply improving liaison, planning and joint working between CAMHS and AMHS.
14	Van der Kamp (2018), UK	To gather mental health workers' and professionals' perspectives, experiences and opinions regarding the transition between CAMHS and AMHS	SSI	8 mental health professionals in 4 different settings. 4 in CAMHS, 2 in one AMHS, 1 in another AMHS, 1 in third-sector organisation (C U Thru) Participants included mental health workers, consultant psychiatrists, team leaders and mental health nurses.	Primary: TA Secondary: Critical Discourse Analysis	A high volume of barriers compared to facilitators to the transition. Transition protocols require updating. Secondary analysis revealed a deficit approach towards transition, whereby deficiencies are given more focus by clinicians.

Quality appraisal

As shown in Table 3, study quality varied, with total scores ranging from 20 to 33 out of 36. The scores assigned may reflect research reporting rather than research quality per se.

All studies reported aims clearly. All reported using a recognised qualitative methodology which was appropriate to the research aims, except for study 2 which utilised workshop activities to gather various data. It was unclear whether the research design of study 11 was appropriate to address the aims as the researchers utilised a questionnaire to capture transition experiences, without discussion as to why they chose this over other more established methods (i.e., interviews).

All but three studies (9, 12, 14) detailed the recruitment strategy used. Although they identified where participants were recruited from, the three studies did not give a detailed account of the recruitment process, making it difficult to determine whether the recruitment strategy was appropriate to address the aims. Gender, age and ethnicity of adult participants were not reported in any study.

Over half the studies reported using semi-structured interviews, with the rest using creative workshops (2), focus groups (6), a questionnaire (11) and interviews (7, 8). One (11) did not report how the data was recorded, with another (8) inferring transcription but not explicitly. This made it difficult for the reader to accurately appraise the research process and results.

Most studies provided sufficient data to support themes. Study 13 referred to an additional online supplement with quotations, however the reader was unable to obtain this. Study 11 provided some data (questionnaire responses) but no quotations, whilst study 12 did not provide quotations to support every sub-theme. All but three studies (4, 7, 11) demonstrated that they had taken contradictory data into account. Apart from study 12, no study discussed data saturation, whereby new accounts no longer provide new insight, but instead only confirm existing themes (Guest, Bunce, & Johnson,

2006). This may be due to sample sizes being determined prior to the research commencing.

Only two studies (10, 14) fully considered the researcher's role in the research process and how this could invoke bias. It is likely that research aims, participant selection, interview questions and/or data analysis are all influenced by a researcher's standpoint. Therefore, the reader's ability to evaluate the studies fully was limited, as underlying epistemological assumptions likely influenced both the method chosen and the findings presented (Scotland, 2012).

Of concern was that five studies (4, 5, 9, 11, 12) did not provide sufficient detail to assess ethical standards, whilst three studies made no mention of ethical approval (3, 4, 12). Due to all studies appearing in peer-reviewed journals, it may be that ethical approval is assumed. However, it is still imperative for ethical standards to be reported so that the reader can evaluate whether participants' rights were upheld.

All studies made a clear statement of findings and a clear contribution to existing knowledge or understanding. Six studies (1, 4, 7, 8, 9, 13) made no discussion of the credibility of their findings, whilst three studies (10, 11, 14) partially mentioned this. Six studies (1, 2, 6, 8, 9, 11) made no reference to future research, whilst although not made explicit, future research directions were inferred from three studies (7, 12, 13). It is surprising that two of the most recent studies (10, 14) were able to make recommendations for future research, whereas earlier studies were not.

Table 3.

Quality appraisal of studies

	Quality Criteria													
Study number	***1***	***2***	***3***	***4***	***5***	***6***	***7***	***8***	***9***	***10***	***11***	***12***	***13***	***14***
1. A clear statement of research aims	2	2	2	2	2	2	2	2	2	2	2	2	2	2
2. Qualitative methodology appropriate	2	1	2	2	2	2	2	2	2	2	2	2	2	2
3. Appropriate research design to address aims	2	2	2	2	2	2	2	2	2	2	1	2	2	2
4. Recruitment strategy identified	2	2	2	2	2	2	2	2	1	2	2	1	2	1
5. Recruitment strategy appropriate to address aims	2	2	2	2	2	2	2	1	1	2	2	1	2	1
6. Clear how data was collected (e.g. interviews, questionnaire etc.)	2	2	2	2	2	2	2	2	2	2	2	2	2	2
7. Form of data clear (e.g. video recordings, tape recordings, notes etc.)	2	2	2	2	2	2	2	1	2	2	0	2	2	2
8. Saturation of data discussed	0	0	0	0	0	0	0	0	0	0	0	2	0	0
9. Critical examination of the researcher role and the potential for bias	0	0	0	0	0	0	0	1	0	2	0	1	0	2
10. Sufficient detail given to assess ethical standards	2	2	2	0	0	2	2	2	0	2	1	0	2	2
11. Mention of ethical committee approval	2	2	0	0	2	2	2	2	2	2	2	0	2	2
12. In depth description of the analysis process	2	1	2	2	2	2	2	2	2	2	0	2	1	2
13. Sufficient data presented to support themes	2	2	2	2	2	2	2	2	2	2	1	1	1*	2
14. Contradictory data taken into account	2	2	2	1	2	2	0	2	2	2	0	2	2	2
15. Clear statement of findings	2	2	2	2	2	2	2	2	2	2	2	2	2	2
16. Discussion of credibility of findings (e.g. triangulation, more than one analyst, etc.)	0	2	2	0	2	2	0	0	0	1	1	2	0	1
17. Clear contribution to existing knowledge or understanding	2	2	2	2	2	2	2	2	2	2	2	2	2	2
18. New areas of research identified	0	0	2	2	2	0	1	0	0	2	0	1	1	2
Total	28	28	30	25	30	30	27	27	24	33	20	27	27	31

Note. *could not obtain online supplement containing quotes

Synthesis

Four main third-order constructs were developed through synthesis: 1) Service cultures; 2) Service resources and gaps; 3) Working relationships between the services; 4) Leaving secure relations and developing new relationships. Table 4 presents third order themes and subthemes and identifies contributing studies. The themes are described below, with supporting evidence from second-order constructs and quotes. The terms CAMHS and AMHS are used to describe child and adult services respectively, regardless of terminology used within the reviewed papers.

Table 4.

Studies contributing to themes and subthemes

	Study number													
Third order theme **Subtheme**	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Service cultures	*	*		*		*	*	*	*	*		*		*
Service resources and gaps														
Guidelines and protocols		*		*								*		*
Training needs and resource gaps	*			*	*				*		*	*		*
Knowledge of the other service	*	*		*	*	*	*		*	*		*		*
Working relationship between the services														
Communication and joint working	*		*		*	*	*	*	*	*	*	*	*	
Responsibility of care			*			*			*			*	*	
Leaving secure relations and developing new relationships						*	*		*	*		*		*

Service cultures

When considering transition, six studies (2, 4, 6, 8, 9, 14) highlighted that service cultures were distinctly different in CAMHS compared to AMHS. CAMHS was seen by clinicians as being more nurturing, protective, comprehensive and family orientated, whilst AMHS were more autonomous, individualised, diagnostic and acute disorder led.

This can lead to narrower eligibility criteria of adult services, which can impact on whether the transition occurs: “if somebody didn’t meet the criteria of

either of those services . . . the only thing that we really have to offer is to go back to the GP." (CAMHS nurse, 1, p. 173)

With AMHS being perceived as being diagnostic and acute disorder led, studies highlighted that this can lead to adolescents disengaging post transition. Transition can lead to the perception that the adolescent is now making a more "permanent move to an illness group" (10, p. 895), with the stigma and labels attached with mental health (12) and the subsequent fear of chronic mental health (10) being cited as reasons for disengagement.

Related to the culture shift, a change in parental involvement was mentioned post-transition (2, 7, 8, 9, 10). Most parents reported experiencing less involvement in their child's care post-transition, compared with extensive involvement in CAMHS, which led to a "fear that they would not be privy to important information about their child's well-being post-transition" (Study 10, p. 895). Parents mentioned feelings of loss and powerlessness at this change (study 8). A nurse in study 9 highlighted the importance of preparing the family for the change: "….often it's not so much the young person that's bothered about the hand over, it's the family….. so it's actually been about involving parents in the idea that you're not going to be around for much longer…" (para. 13) In contrast, some parents in study 8 felt relieved at no longer having the responsibility.

As well as the parent experiencing a change in role, the young person experiences increased autonomy and greater responsibility for their care, as referenced in four studies (7, 9, 10, 14). Parents were concerned about the adolescent's maturity levels regarding choosing whether to have parental involvement and deciding for themselves whether they wish to transition to AMHS (7). Clinicians in study 9 acknowledged the benefit of family inclusion in AMHS, subject to the adolescent's wishes, which is often relationship dependent (7). Study 14 highlighted that even if the adolescent decides to involve their parents in their care post-transition, the culture difference between services means the type of involvement differs to CAMHS.

To help prepare the young person for taking on more responsibility post-transition, clinicians viewed it essential that they take greater responsibility for

their care in the latter stages of CAMHS (10), however there was acknowledgement that CAMHS clinicians may find it difficult to change their long-standing approach (14): “In CAMHS we sometimes treat the older adolescents as if they are quite little […] [we should] try and get them ready to be treated more as fully grown adults” (CAMHS clinician, 14, p. 17).

A CAMHS clinician in study 6 seemed to suggest that rather than extensive preparation, transitioning between services with two different cultures is advantageous enough:

> The advantage with transition is a step in the right direction. Here we are very cherishing . . . they remain kids as long as they stay here. We don’t give them any favors into adulthood. When they enter there [GenP] it is another step. (p. 105).

Service resources and gaps

All but three studies (3, 8, 13) highlighted service resources and gaps affecting transition, in relation to three sub-themes, “guidelines and protocols”, “training needs and resource gaps” and “knowledge of the other service”.

Guidelines and protocols.

Clinician participants across four studies (2, 4, 12, 14) referred to transition guidelines and protocols, or a lack thereof. This was in terms of a need for up to date (14) transition protocols (12) developed with clinicians (4), and formal structures other than a medical referral letter (12). Where protocols were in place, clinicians wanted more support to honour transition policy (2) and highlighted confusion about implementation (14): “Ideally it [the transition] starts when they are 17 and a half. That is the theory, but it does not always work like that..*”* (CAMHS clinician, 14, p. 15).

Training needs and resource gaps.

In studies 5, 9, 11 and 12 there was a perception that AMHS clinicians need more training. Professionals (9) suggested that AMHS clinicians experience anxiety and lack confidence in managing adolescents who transition to their service, whilst specific training needs for AMHS staff identified (12)

included developmental theories, adolescent issues, child protection and consent to treatment.

Clinicians identified perceived training needs for AMHS practitioners, including Autism Spectrum Disorders (ASD) (5) and ADHD (1), with parents also identifying scarce clinician knowledge of ADHD (11). Resource gaps were also identified for individuals with intellectual disabilities (4, 12), and ASD (5) which could impact whether a transition occurs:

> I think what's really hard is that there are no providers within our community that are autism adult providers. There is one good psychiatrist in town…But other than that, there is really no one else that's taking on these guys. (5, p. 267).

However, resource gaps appeared to be location dependent, with study 14 reporting that those with ADHD or intellectual disability experienced the smoothest transition because there was no resource gap. There appeared less of a barrier to transition when services other than AMHS were available, such as a project to provide support to those who do not meet AMHS criteria (14), leading to a clinician in study 14 concluding "It is a bit of a postcode lottery whether you get a good transition or not" (p. 16).

Knowledge of the other service.

Knowledge of the other service was mentioned in ten studies. CAMHS clinicians highlighted a lack of knowledge about AMHS service structures and availability (1, 6), which can lead to inappropriate (4) or "shot-blast' (12) referrals, as demonstrated by a participant in study 14: "If I had a better idea, I might have some ideas about whether I am referring the correct patients and whether I am doing it the right way*"* (p. 18)*.*

In studies 1, 2, 4, 10, 12 and 14 there was a perception that AMHS offer a narrower service range than CAMHS, by operating at higher eligibility thresholds with a greater focus on those experiencing severe mental illness. This can lead to adolescents seen in CAMHS not being eligible to receive support when they reach 18 (1), which study 4 describes as a "falling off the cliff experience" (p. 14). Study 2 clinicians highlighted that "only the most unwell will be accepted" (p. 8).

Clinicians' uncertainty about the other service can be conveyed to adolescents and families (6) due to them not being able to give detailed information about the adult service being transitioned into (7): "What information did you get about GenP? None, it feels like I'm walking into darkness*."* (parent, 7, p. 4). The lack of information being given by CAMHS staff to families and adolescents about AMHS means they can arrive with unrealistic expectations (9).

Several ways to improve knowledge of each other's service were suggested, including clinicians having experience working in both CAMHS and AMHS (9), having routine joint CAMHS/AMHS team meetings (2), and compiling a list of providers who are willing to take on particular patients (5).

Working relationship between the services

All but three studies (2, 4, 14) referred to the working relationship between the services as a key part in the transition. This was in relation to two sub-themes; "communication and joint working" and "responsibility of care".

Communication and joint working.

Communication and joint working was relevant in all but three studies (2, 4, 14).

Studies 10 and 11 share concerns regarding the communication gap between CAMHS and AMHS which can be an obstacle to transition: "…there is a gap of communication and collaboration between CAMHS and adult services, there is, and I think that, that drips into [Int.Everything] into everything*"* (CAMHS clinician, 10, p. 897).

AMHS clinicians (9) stressed the importance of information sharing by all concerned in transition, particularly around risk. However, professionals highlighted that exchanging of service user data between CAMHS and AMHS is often poor (3), for reasons such as different IT systems (9, 12). In some instances, AMHS professionals were not always taking the medical record from CAMHS, whilst at other times professionals at AMHS had been denied access to medical records (6). The lack of communication between CAMHS and

AMHS, and AMHS professionals having little interest in reading medical records from CAMHS led to parents feeling powerless and frustrated (8). Using a care binder to pass between services was suggested to improve information sharing (5).

A need to increase joint working between CAMHS and AMHS was mentioned in five studies. Despite recommendations of joint working during transition, and clinicians (3) and parents (13) valuing this, strained professional relationships and lack of resource means that this rarely happens (10): "…getting the time to do that and the professionals together to do that is often … difficult." (AMHS clinician, 3, p. 255). Parents wanted cooperation between CAMHS and AMHS to be based on individual need rather than professionals' working schedules (7). CAMHS staff identified a barrier to joint working being AMHS rigidity of only working with people once they reach 18 (1). A useful working practice to encourage joint working was placing an adult or transition clinic in a child setting (5).

Responsibility of care.

Issues around responsibility of care were prevalent in five studies. Shared responsibility between AMHS and CAMHS care-coordinators was suggested as a facilitator to transition (9), but clinical governance issues (3) and difficulties deciding medical responsibility (6) can prevent this. Study 13 clinicians shared this view, expressing concerns about "responsibility for someone on your case-load, should something go wrong" (p. 309). A nurse in study 9 highlighted that AMHS staff can be reluctant to take on responsibility during transition.

> It's difficult if the CMHT member coming is paying lip service, they don't expect to take on any responsibility or will have to go back to their manager, or they haven't thought who would be the young person's care co-ordinator. It's a bit random really. (para. 25).

It was suggested that a way to combat responsibility of care may be for a transitional worker/team to bridge the gap between the two services (12).

Leaving secure relations and developing new relationships

Six studies (6, 7, 10, 12, 14) referred to leaving secure relations and developing new relationships as part of the transition.

Parents were concerned about transition due to the termination of feeling secure in CAMHS and having to develop a new trusting relationship with AMHS (7), with some desiring a year's overlap on each side of age 18 to allow relationship building prior to transition (12). A CAMHS clinician in study 14 highlighted that at transition a young person's "anxiety can be heightened" (p. 18). Subsequently they can experience "[…] difficulties building up those new relationships" (AMHS clinician, 14, p. 18). There was a desire from parents for AMHS professionals to visit the young person in CAMHS where the family felt secure to start relationship development prior to transition:

> It's GenP that should come to CAP and tell what it's like…they forget that, they do the opposite…it's not CAP that should tell us about the other…because that's when you feel you're welcome, now you feel like you've been rejected. (parent, 7, p. 4).

However, there are often minimal opportunities to build connections with AMHS staff prior to their first appointment due to an absence of transition planning meetings (10). Despite this, clinicians advocated shared care co-ordination for three months to facilitate weaning away from CAMHS and developing new relationships in AMHS (9), or follow-up contact with their CAMHS clinician post-transition to decrease feelings of abandonment (6): "Maybe we can share some things, okay if they start to come to us but don't quit at once at CAP, a little more cooperation can you wish." (AMHS clinician, 6, p. 107). Empathy and relationship building in AMHS was highlighted as difficult due to over-stretched work loads and shorter appointment times (10).

Discussion

This review has systematically explored the evidence regarding professionals' and parents/carers' perspectives relating to their experiences of adolescents making the CAMHS-AMHS transition, to gain a more comprehensive understanding of the transition experience. Four themes, with

subthemes, were identified that synthesise captured transition experiences. Clinicians and parents highlighted transition to be a turbulent time, attributed towards how services are set up. Of concern were cultural differences and communication difficulties between CAMHS and AMHS, as well as a lack of knowledge, responsibility, guidance, protocol and resources. In addition, the family and young person leaving secure relations and developing new relationships was hindered by a lack of care co-ordination and overstretched workloads.

Contribution to the literature

By using metasynthesis, the current review has moved beyond previous narrative reviews on transition. The review by Reale and Bonati (2015) included studies on rates, descriptions, outcomes and experience. They concluded that transition difficulties occur for different reasons across countries. The review by Paul et al. (2015) described each study's findings individually. By focusing solely on experience, and conducting a metasynthesis, the present study has developed new meaning via third-order themes which appear to be relevant across cultures, whilst moving beyond describing transition experience on a study-by-study basis.

A critique of the review might be that it did not consider adolescents' experiences. However, the recent systematic review conducted by Broad et al. (2017) encompassed these experiences; the current review builds upon this by considering perspectives of the other parties involved in transition.

Broad et al. (2017) highlighted that adolescents found transition to be turbulent and desired flexible transition timing and more joint working. By seeking professionals' perspectives, the current review also offered reasons as to why it is difficult to achieve desired outcomes. For example, joint working does not happen due to a communication gap between CAMHS and AMHS, difficulties sharing information, strained professional relationships and a lack of resource. It would not have been possible to highlight these barriers by considering adolescents' experiences alone.

Whilst Broad et al. (2017) found that a sudden shift in parental involvement can be difficult for adolescents, the current review highlighted that

this process can be difficult for parents, demonstrating the importance of considering parents in the transition process. The current review also found that parental views were not homogenous, with some parents concerned about their involvement changing, whilst others felt relieved. Each transition should therefore be managed on a case-by-case basis in terms of parental involvement.

The current review also surpasses Mulvale et al.'s (2016) deductive review, which used pre-conceived ideas about care philosophies, by remaining inductive and broad. This allowed themes beyond care philosophies to be developed. However, despite only sharing four studies with Mulvale et al.'s (2016) review, service culture was still highlighted as a concern and thus formed one of the themes. Service culture is therefore a key part of transition experience in the broader transition literature and should be an area of priority to improve transition experience.

Theoretical and clinical implications

Results indicate that service configuration and transition management does not allow for gradual ceasing of old relationships in CAMHS and development of new ones in AMHS. Instead, families and adolescents experience feelings of insecurity, loss, mistrust, abandonment and feel unwelcome at transition. Considering these findings using attachment theory (Bowlby, 1982), it is probable that adolescents and their families have formed attachments with their CAMHS clinicians (Adshead, 1998). Abrupt endings of these relationships are likely to cause distress, negatively impacting the transition experience. Results suggest overstretched workloads can affect relationship building and empathy in AMHS, thereby threatening the restoration of emotional safety. Additionally, resource issues and different eligibility criteria can mean that some adolescents are no longer eligible for support in adult services, meaning no opportunity for restoration of emotional safety. This all serves to highlight the importance of improving the CAMHS-AMHS transition experience, taking into consideration individuals' relational attachment patterns. There should be an emphasis on facilitating positive endings to longstanding relationships over a period of time, as well as enough time being given to form

new attachments in AMHS. This may be achieved through joint working or care overlap.

To overcome the identified barriers to a smooth transition, service innovation is needed. Ideally, in the context of attachment theory (Bowlby, 1982), rather than separate services there would be one service for all age groups, promoting consistency and stability. This would prevent relationships ceasing, whilst alleviating many of the issues regarding differences in services, communication deficits and care consistency. This should be considered when re-commissioning services. However, at present services are split into child and adult services. Therefore, in the short-term there should be a focus on enhancing CAMHS-AMHS communication and improving knowledge of each other's service. Professionals should aim to network, making communication easier and joint working more possible at transition. Increasing CAMHS professionals' knowledge of AMHS should assist with correct referrals being made, whilst also enabling professionals to better explain and prepare families and adolescents for AMHS. AMHS professionals should also be offered training on working with adolescents (McLaren et al., 2013), developmental theories (Richards & Vostanis, 2004) and specific disorders (Kuhlthau et al., 2015).

Transition guidance/protocols should be updated (van der Kamp, 2018), with results suggesting it would be beneficial to involve clinicians in their development. Transition guidance was found to be difficult to implement (Dunn, 2017), and also caused confusion for clinicians (van der Kamp, 2018). Involving clinicians in the production of guidance could help them to feel less marginalised (Kaehne, 2011) and give them the opportunity to highlight areas which are difficult to achieve in practice. These steps may make clinicians more likely and able to implement guidelines. The provision of information being given to service users and carers should also be a key part of any protocols, as parents feel that information is lacking at transition (Lindgren et al., 2014).

Service commissioners should be mindful of the AMHS resource gap which appears to exist for those with neurodevelopmental disorders. Although this is location dependent, care equality should be promoted by ensuring that a service is available for these adolescents to transition into.

Limitations and future research

There is a gap in the literature for capturing all parties' CAMHS-AMHS transition experience for those with neurodevelopmental disorders, despite it being highlighted that there can be a lack of adult services for these individuals, and transition being more difficult for them (Swift et al., 2013). This may be due to many not making the transition as there is no adult service available. Future research should focus on capturing the experiences of those with neurodevelopmental conditions (along with their parents and clinician) when they leave CAMHS and several months later. This would highlight whether they managed to make a successful transition and capture experiences.

The process undertaken to conduct the present review has several limitations. Excluding non-English studies meant that two studies (Armbruster & Freyberger, 2017; Gerritsen et al., 2017) were excluded, despite their titles and abstract appearing relevant.

The review only sought out literature from peer-reviewed journals as this has already been through a quality appraisal process. Whilst this ensured a high quality of included studies, excluding grey literature might have meant that the review failed to capture some transition experiences.

The UK is over-represented in this review (nine out of 14 papers) and this should be borne in mind when attempting to generalise the results elsewhere. Generalisability is also likely to be limited due to the large variance in services and policies nationally and internationally.

The evidence within the reviewed studies offered more about transition obstacles as opposed to positive experiences. Even in studies seeking out both facilitators and barriers, there tended to be a higher focus on barriers, suggesting it may be that deficiencies are given more focus by clinicians (van der Kamp, 2018). It is therefore unclear whether the current review is more biased towards barriers due to clinicians and researcher focus, or whether it is a true reflection of services at present. Future research should focus on facilitators to transition, enabling learning from positive transition experiences.

Although the review aimed to treat all papers equally, those with a higher quality score were more heavily relied upon in the synthesis. Lower quality

papers tended to provide evidence for third-order constructs as opposed to offering new themes. Papers with fewer quotes were under-represented, with more quotes taken from papers which provided an abundance of these. Future qualitative research should focus on reporting more quotes.

The quality appraisal process highlighted suggestions for enhancing the quality of future qualitative research and how it is reported. It is recommended that future studies report gender, age and ethnicity of participants, pay more attention to critically examining the researcher's role and the potential for bias, ensure sufficient detail is reported to assess ethical standards, discuss in greater detail the credibility of findings and identify areas for future research.

Conclusion

The findings suggest the cultural difference between CAMHS and AMHS is a barrier to smooth transition. Attachment theory would suggest having one service for children and adults. However, at present, greater focus needs to be given to managing the ending of relationships in CAMHS and developing new relationships in AMHS. There is a desire for better preparation for transition, more joint working and better communication between CAMHS and AMHS. Many of these difficulties could be alleviated by increasing cooperation between CAMHS and AMHS professionals. Resource gaps also exist when adolescents reach adulthood, particularly for those with neurodevelopmental conditions, which should be an area for future service development and research. There is also a desire for more training of adult providers to increase their confidence of working with adolescents. This could aid relationship building post-transition which may help improve transition experience.

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JOURNAL PAPER

Service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training.

Abstract

Purpose: Extant literature exploring service user (SU) involvement in clinical psychology training has been limited by its sampling from singular training programmes and its restricted application of psychological theory. This research seeks to counter limitations by exploring SUs' experiences across multiple clinical psychology training programmes and by deductively applying psychological theory relating to power, recovery, identity, and group development.

Design/methodology/approach: Semi-structured interviews were conducted with fourteen participants. A deductive thematic analysis was used to analyse qualitative data.

Findings: Five main themes were identified: Environment determines sense of safety; Meeting challenges; Sense of purpose, Worth and value; The person you see now is not the person I was; and Wanting to break the glass ceiling.

Research limitations: SUs who co-identified as carers are under-represented and the sample does not contain SUs who were no longer involved in training.

Practical implications: It is important that the environment fosters psychological safety for SUs, via positive and supportive relationships with trainees and staff, with SUs being treated as equals and financially reimbursed as such. SUs and professionals need to explore managing and sharing power to enable SUs to feel valued and to reap benefits from involvement, including developing a positive sense of identity.

Originality: The research is part of the early literature exploring SUs' experiences of involvement in clinical psychology training and is the first to specifically explore the personal effects of involvement across multiple programmes.

Keywords: Service user, Involvement, Clinical psychology training, Experiences, Recovery, Identity, Power.

Introduction

Service user involvement

Service user involvement (SUI) is common-place in mental health services and in the training and education of healthcare professionals in the UK and abroad at the micro (own care); meso (health service); macro (health policy); and meta (education) level (Tambuyzer *et al.,* 2011). To measure and locate the level of SUI, the Ladder of Involvement was proposed by Tew *et al.* (2004), suggesting five stages to involvement; ranging from level one: no involvement, to level five: partnership. However, whilst this model can be applied well when considering power, it might fail to recognise the complex, dynamic and evolving nature of involvement (Tritter and McCallum, 2006).

Involvement in clinical psychology training

The Health and Care Professions Council (HCPC) now includes service user (SU) and carer involvement as part of its education standards (HCPC, 2017) formalising the requirement of their inclusion in the training of the professionals they regulate which includes clinical psychologists[1]. As well as being a requirement of the Health and Care Professions Council (HCPC, 2017), the British Psychological Society's (BPS) accreditation criteria for clinical psychology doctorate training programmes states *"*service users and carers should inform and participate in the delivery of the curriculum*"* via involvement in research, academic and clinical activities (BPS, 2019, p.25). The focus on the delivery of the curriculum suggests that the accreditation criteria encourages involvement for the benefit of trainees rather than SUs involved.

Indeed, previous research has predominantly focussed on the trainee experience of SUI and the implications this has for trainees' learning and attitudes (Harper *et al.,* 2003; Schreur *et al.,* 2015; Tickle and Davison, 2008). There is limited evidence on the potential costs or benefits for involved SUs to support them to make an informed choice about their involvement or to inform programmes. Evidence exists suggesting involvement activity actually falls short of aspirations (Briggs *et al.,* 2017). Whilst providing education and training is a professional role,

[1] See extended paper for additional information on SUI

when this is being delivered based on personal experiences as a SU, its effects, both risks and benefits, are likely to be personal too.

Potential challenges include finding the educational setting daunting (Holttum *et al.,* 2011), power struggles between SUs and academics (Lea *et al.,* 2019) and feeling powerless and thus invalidated due to restricted access to students and limited decision-making capacity (Campbell and Wilson, 2017). Reported benefits include feeling valued and heard (Lea *et al.,* 2019), increased confidence and assertiveness (Holttum *et al.,* 2011); developing a powerful sense of self by positively shaping future psychologists and making a difference to mental health services and therefore other SUs (Campbell and Wilson, 2017) [2, 3]

Psychological theory related to SUI

It is apparent that particular psychological theories might be applicable when considering personal effects of SUI, but these theories have not previously been considered in detail in when exploring SU experience of involvement in clinical psychology training. Considering the history of profound power inequalities between SUs and mental health professionals (Felton and Stickley, 2004) and with empowerment and recovery being highlighted as key outcomes of SU involvement (Tambuyzer *et al.,* 2011), it would seem prudent to consider theories of power and recovery and how these relate to the involvement experience[4].

Lukes' (1974) dimensions of power could be applied when attempting to understand the personal effects of involvement in clinical psychology training, as it is likely that SUs will be party to decisions about the amount and type of involvement and potentially aspects of the curriculum. Relevant aspects of Luke's theory include decision-making power (ability to modify the behaviour of others) and non-decision-making power (consciously or unconsciously shaping an agenda which limits decision making). Furthermore, French and Raven's "bases of social power'' (1959) appears relevant, in particular 'expert power' – perceiving that another person (either the SU or professional) has special knowledge or expertise. In addition, a consideration of 'informational power' (Raven, 1965); the

[2] See extended paper for expanded methodological critique.
[3] See extended paper for more study information.
[4] See extended paper for extended theoretical discussion.

idea that a person of power is in a position to share, withhold, distort, manipulate or conceal information.

Personal recovery is subjective and thus there is no universal definition, however it is often regarded as a process involving re-engagement with life, improved coping and a restoration of sense of self and purpose in life (O'Connor and Delaney, 2007), arguably factors which that involvement work could facilitate. An empirically based conceptual framework of personal recovery in mental health, the CHIME framework (Leamy *et al.,* 2011), consists of connectedness; hope and optimism about the future; identity; meaning in life, and empowerment.

When considering the personal effects of SUI, it also makes sense to consider how involvement might impact on one's sense of identity. Identity has been defined as "the set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person." (Burke and Stets, 2009, p.3). Having a positive sense of social identity (a sense of meaning, purpose and belonging) is linked with positive psychological consequences (Haslam *et al.,* 2009).

Involvement entails "in groups" and "out groups" in terms of SUs, staff and trainees with social identity theory (Tajfel and Turner, 1979) proclaiming similarities to the in group and differences to the out group are exaggerated to enhance identity. SUI can influence identity due to changes in group identification (Tse *et al.,* 2012). However, challenges to developing a positive identity in SUI include how professionals perceive SUs' mental health, their shift in role and how SUs re-orientate themselves to their new group, which can be a stressful process (Iyer *et al.*, 2008)[5] .

One might also expect that SUI in clinical psychology training would elicit experiences specific to group processes that might be understood using Yalom's framework (Yalom and Leszcz, 2005), namely universality, altruism, imparting information, the development of interpersonal skills and group cohesion.

[5] See extended paper.

Rationale and aims of current research

Only recently has research started to consider the effects involvement may have on SUs and with some authored by SUs themselves (Lea *et al.,* 2019), it might be said that this reflects a shift in power in the involvement research sphere. Extant research has been limited by samples derived from singular training programmes and with a lack of application of psychological understanding.

The present study aims to build on previous findings by specifically exploring the personal effects that involvement may have on SUs/carers and by deductively applying psychological theory around power, recovery, identity and group development to help explore and understand the personal effects of involvement utilising samples from multiple programmes. This will inform future involvement in clinical psychology training and help shift the focus to considering how to optimise involvement for SUs/carers as well as trainees. It may also inform the choices of those considering involvement, based on an understanding of other people's experiences of the personal impact.[6]

Methodology

A qualitative approach was taken to the research. Data was gathered via semi-structured interviews and analysed using thematic analysis (TA) based on the principles suggested by Braun and Clarke (2006).

Epistemological stance

The researcher took a critical realist epistemological stance[7].

Reflexivity

The main researcher (a trainee clinical psychologist) approached this research from the position of experiencing training and the involvement that SUs/carers provide. The researcher was mindful of their professional employment, which may have influenced how SUs/carers interacted with them compared to a peer researcher.[8]

[6] See extended paper for expansion on rationale.
[7] Further information on the epistemological stance can be found in the extended paper.
[8] See additional note on reflexivity in extended paper.

Quality monitoring

Quality was monitored by the researcher throughout the research process by keeping a research journal, using supervision, and by using the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018), of which all quality criteria were met.[9]

Participants and recruitment

A sample of around 12 is deemed sufficient for a TA (Ando *et al*., 2014), thus the study aimed to recruit 10-15 SUs/carers aged 18 or over who were involved in clinical psychology training for at least six months, with recruitment being stopped when data saturation was reached.[10] Study information was disseminated via email correspondence (Appendix A) with course staff who oversee SUI on their respective courses and via the Group of Trainers in Clinical Psychology Involvement Subgroup mailing list[11]. Purposive sampling meant they were asked to disseminate via email and in SU meetings/forums a recruitment advertisement (Appendix B) to SU/carer representatives.

Participants were offered a £10 multi-store gift voucher for taking part[12]. Interested prospective participants who met the inclusion criteria were asked to email or telephone the researcher for more information. Participant information sheets (Appendix C) were then sent and participants had the opportunity to ask questions before informed consent (Appendix D) was sought.

Attempts were made to recruit (via snowballing) those who had left SUI. Participants were asked to pass the study information sheet to any SU/carers who were previously involved in training who they still had contact with. None were recruited via this method.

Procedure

The study received ethical approval from University of Nottingham's The Division of Psychiatry & Applied Psychology (DPAP) research ethics sub-committee (Appendix E).

[9] See extended paper for more detail on quality monitoring.
[10] See extended paper for further discussion on sample size.
[11] Additional information on the mailing list can be found in the extended paper.
[12] See extended paper for rationale.

Demographic information was gathered[13] . Four interviews were conducted face-to-face (at the researcher's University) with the remaining ten conducted via telephone. The interview schedule (Appendix F) contained non-directive, open ended questions aimed at gathering detailed data grounded in participants' experiences of personal motivations for becoming involved in clinical psychology training; what involvement entails; and whether and how involvement links to SUs' self-perception, identity and sense of empowerment[14]. Interviews lasted between 18 and 94 minutes (average 31 minutes). The interviews were audio-recorded and transcribed verbatim by the researcher with the aid of transcription software. By the fourteenth interview content was relatively similar with no novel findings.

Analysis

A TA approach was used based on the principles suggested by Braun and Clarke (2006). The current research used a deductive approach to data analysis, with theoretical propositions informing the analysis, with a specific focus on theories relating to potential personal effects of SUI (e.g. power, recovery, identity, group development). All data (both confirmatory and disconfirmatory) related to the theories was analysed.

Braun and Clarke's (2006) six phases were followed to analyse the data;, data familiarisation; code development; collation of codes into potential themes; checking themes in relation to the coded extracts and the entire data set; the development of a thematic map and refining themes[15].

Results

Participant characteristics

Fourteen participants from eight programmes took part, and none withdrew (see *Table 5* for demographic information). Participants had been involved for between seven months and 10 years (mean = 3.88 years). Six participants were still using services. Those no longer accessing services last did so between 10 months and 10 years ago (mean = 3.75 years ago). Participant experience included

[13] See extended paper for details.
[14] See extended paper for question development.
[15] See extended paper for more information on analysis, including rationale for choice of method.

accessing a wide range of both private and statutory services. Thirteen had seen a clinical psychologist.

Themes

Five themes were identified, some with subthemes: Environment determines sense of safety; Meeting challenges; Sense of purpose, worth and value; The person you see now is not the person I was; and Wanting to break the glass ceiling.[16]

Theme 1: Environment determines sense of safety

It was evident that the environment determined how safe individuals felt in their involvement, with a particular focus on the importance of psychological safety.

Subtheme 1a: Supportive relationships

Relationships and connections built with trainees and staff were key in determining individuals' sense of safety. Having 'stimulating discussions' (*Kimberley*) with trainees was important to participants, and it was highlighted how trainees are 'receptive and understanding' (*Megan*) and ' very respectful' (*Emma*), meaning there's a sense of enjoyment in interacting and working with trainees (*Kimberley*, *Dawn*). However, being asked to give immediate feedback to trainees can be 'awkward' (*Craig*), which might be due to not wishing to threaten the sense of safety that SUs feel as a result of their positive connections with trainees.

'A very supportive ethos' (*Sheena*) created by staff was important, with a sense that even though staff 'have so much on…' (*Kimberley*), time was always made for SUs if they needed support. However, there was a desire for this to not be mental health support:

> I don't think it's fair to do, is to use the tutors as psychologists to kind of work through my own problems with. I don't think that's why we're here. (*John*).

[16] See extended paper for a more detailed description of themes and subthemes using additional illustrative quotes from participants.

Table 5. Sample characteristics

Characteristics	*Category*	*Participants (n)*
Gender	Male	6
	Female	8
Age bracket	25-29	1
	30-34	1
	35-39	1
	40-44	2
	45-49	1
	50-54	1
	60-64	4
	65-69	2
	75-79	1
Ethnicity	White British	7
	British	2
	Asian British	1
	British Indian	1
	Mixed	1
	Italian	1
	German Syrian	1
Service user or carer	Service user	12
	Carer	0
	Both	2
Affiliated programme (anonymised)	A	4
	B	2
	C	2
	D	2
	E	1
	F	1
	G	1
	H	1
Mental health services used[17]	Psychotherapy	7
	Counselling	1
	Psychiatry	5
	Perinatal	1
	Inpatient	3

[17] Some participants used multiple services and are subsequently represented more than once

Table 5. (Continued)

Community learning disability services	1
Community mental health teams	3
Early intervention	2
Eating disorder services	1
Personality disorder services	1
Pain services	1
Crisis teams	2

This might be because of a desire to be treated as equal members of staff and 'feel like part of the workforce' (*Russell*).

There was however a desire for support if something was triggering:

> [if something] is a bit triggering, I can pick up the phone and talk to someone, I've got phone numbers that I can talk someone at the university. (*Dawn*)

Subtheme 1b: Group dynamics

Several participants described a sense of belonging and mutual connection to a group of involved SUs which helped develop psychological safety; 'And we all have very similar struggles and have faced all sorts of things, and there's that feeling of group survivorship, I think' (*Dawn*).

Despite this, some participants described feeling overwhelmed and anxious when first joining a SU group which might be as a result of power dynamics within the group:

> Like, initially when I first started, I was a bit nervous and felt the power dynamics. Like, it felt like some people had more of a say than others… (*Abigail*).

Additionally, seeing SUs at different stages of recovery to oneself can be difficult:

> But the bad thing would be perhaps I would feel sorry for these people a little bit because they haven't been out that long like two or three months in one case. And it's kind of it, it does show that that person doesn't really want to fit into the community again. So it's a little bit depressing, but I keep quiet and think 'ah, they have to go through these things' (*Russell*).

Whilst there is a sense of survivorship in involvement which can support a sense of safety, participants conveyed a sense that there needs to be active awareness and management of dynamics within the group by group members and programme staff to promote both existing members and newcomers to feel safe:

> And so it's about handling dynamics of a group where there are, I wouldn't say really strong personalities, people with extreme needs and being able to still find a place where you can be yourself but not get involved in their problems… And I do think that it's a lot to do with the leadership…Because she's a strong leader, it doesn't get out of hand. (*Joy*)

Thus, relationships and connections with staff and trainees were key in determining individuals' sense of safety in involvement. This was particularly important considering participants described how the environment can be triggering and have an emotional impact meaning support may be needed. However, psychological safety through shared experiences cannot be assumed and must be promoted through active management of group dynamics and mental health difficulties arising from the work.

Theme 2: Meeting challenges

It was indicated that there are challenges to be met within involvement, some of which can result in uncertainty, anxiety, worry, feeling scared and feeling drained.

One such challenge was being involved in course selection processes, which as well as 'wearing me out a little psychologically' (*Ross*), poses a challenge in the context of having an increased sense of responsibility alongside those who are perceived to have more knowledge and more power (e.g. professionals):

> …there were a few instances where I realised that I had scored very differently from the other members of the panel and I felt dreadful. And I wanted so sort of rush around and change everything because I was getting it wrong. I was really getting it wrong. And it was, I got into quite a panic about it... I was thinking, oh, my gosh, what if what I've said is, you know, means someone doesn't get on the course and so on. (*Kimberley*)

However, it was indicated that over time increased confidence arose as a result of realising that those with a higher educational level do not necessarily have more knowledge, thus feeling empowered:

> And I think my confidence in actually what I know, what I experienced, what I've experienced from other people is valid and is, I think initially, I was a little bit like, oh, am I am I allowed to say this? Like, you know, when people are like sat there with degrees and done research projects and this, that and the other, like oh they've got loads more knowledge than me. But actually over the years I've realised that actually that's not necessarily the case. (*Claire*)

Despite the emotional impact of challenges to involvement, involvement generally had a positive emotional impact, for example David described 'I've enjoyed every minute of it [involvement] that I've done there.'

Whilst involvement can result in challenges that lead to an array of emotions including initial self-doubt, meeting these challenges can lead to a sense of empowerment and increased confidence. This is likely to result in a change in identity.

Theme 3: Sense of purpose, worth and value

All participants referred to feeling a sense of purpose, worth and value as a result of involvement.

Subtheme 3a - Feeling listened to and valued

A sense of worth and value was contingent on feeling listened to by course staff and trainees: 'And the teaching staff listen. They don't go 'hold on a minute, I'm the professional' ' (*Jamie*).

Although rare, tokenistic involvement where decisions could not be influenced led to feeling less valued:

> …when things are tokenistic it does feel like you're not able to contribute and you're not valued there. Because if all the outcomes have already been decided, it's like you're just there for the sake of it… (*Abigail*)

The issue of being paid equally was vitally important to feeling valued, perhaps suggesting this goes someway to addressing any power imbalances. Whilst on some courses those involved were paid the same rate as psychologists, others described the voluntary nature of involvement or not being paid for partaking in selection whilst professionals were:

> you don't get paid for it… But I know that there's some people that are working for the NHS that…still get their working hours included whilst they're doing the interviewing… so I kind of felt it wasn't fair that some people were getting paid for it and some people weren't. (*Ross*)

Subtheme 3b - A positive way to feed back into the system

An increased sense of purpose was related to being able to put their difficulties to good use:

> I think by really feeling that this was sort of a positive way to feed back into the system something that had been such a negative for the bulk of my life, to find a positive way of framing that was really useful. And so yes it has been very, it has very much affected how I feel about myself. (*Sheena*)

A sense of purpose was particularly important when other aspects of life were extremely difficult:

> …when I feel like I'm failing at everything else I'm like, actually look at me, I've got several paid roles and I'm doing this, people are asking my opinion on this and that feels really good. It's a really big boost. (*Claire*)

The sense of purpose was also important in confronting potentially ageist views whereby society might perceive that older people do not have much to contribute:

> …because people say, what do you do? And I tell them what I do. Well, I'm with the course at the university and it's, it feels that I'm not just some old guy who's finished, you know. (*John*)

Involvement leads to feelings of worth and value, particularly when ideas are listened to by staff and implemented, suggesting being treated as experts and having decision-making power leads to empowerment. SUs feel less worth and value when they are not fully listened to or ideas are not implemented, or when their contribution is not financially rewarded. Involvement also leads to a sense

of purpose, largely from being able to put their difficulties to good use in an altruistic way, thereby helping build a more positive identity which is particularly important for those later in the lifespan or when there are difficulties in other aspects of their life.

Theme 4: The person you see now is not the person I was

The overarching commonality amongst participants was that their mental health and social functioning had improved as a result of involvement; ‘I didn't realise this would be a kind of by-product of my involvement, but it's helped my mental health enormously’ (*John*).

Subtheme 4a: A game changer for personal growth and development

Aspects of personal growth were identified as a result of involvement amongst several participants including improved social skills and social functioning, decreased isolation, increased confidence, and further development opportunities. All of these factors seem to have led to an improvement in quality of life and the development of a positive sense of identity, e.g.:

> …the person you'll see now is not the person who I was… I'm developing as a person mentally, physically and socially and everything, all because of [involvement]. It's, it's been a massive game changer. And I've suffered a lot from loneliness as well and knowing that, in a couple of weeks’ time, I've got that in my diary, and it may be only an hour, but I can go to somewhere where I'm respected and I feel valued and I value myself, that's the key thing. (*Jamie*)

Increased confidence as a result of involvement has also led to pursuing other opportunities, such as Dawn volunteering at a local foodbank, or John engaging in further involvement activities; ‘So it sort of gave me the confidence to sort of do those things [other involvement]’ (*John*).

Other benefits outside involvement include confidence to continue recovery:

> It's given me a little bit of confidence to do other stuff and, pursue my recovery outside of [involvement] that I wouldn't have been able to do without [involvement]. Without [involvement] I wouldn't be in the fantastic place of recovery that I am at the moment. (*Jamie*)

Subtheme 4b: Relating to difficulties in a different way

Relating to difficulties in a different way was an important consequence of involvement which helped participants redefine their sense of self and identity by feeling less stigmatised and having more self-compassion.

Several participants indicated that by being involved in clinical psychology training, they had access to theoretical knowledge which is explained and discussed which then enables them to better understand their own difficulties. There was a sense that this information was not readily shared with SUs across a range of mental health services, meaning they were somewhat in the dark regarding their difficulties:

> …when you're accessing services... things are not explained to you. Whereas when you're taking part with the teaching programme, things are explained… And therefore, I think I've understood quite a lot more about the way, the way I function. (*Kimberley*)

In addition, accessing new explanations led to 'being kinder to myself' (*Megan*), with some of the stigma around participants' difficulties lessened:

> I could see clearly why things had happened as they happened and why I was as I was. And that was wonderful. I mean, it took it took a lot of the stigma away for me. It took a lot of the blame away for me as well. (*John*)

Subtheme 4c: Reengaging with skills that I thought had gone

Involvement provided the opportunity for participants to reengage with skills they thought they had lost, thus helping them restore their sense of self and rebuild their sense of identity:

> I am a trained teacher... So here I was using something difficult that had happened to me, the positive using some skills that I had that I had forgotten about because they'd become that lost in my illness. (*Claire*)

Evidently, involvement offered opportunities that gave rise to a shift in identity through personal growth, understanding and relating to difficulties in a different way and reengaging with aspects of their identity they thought they had lost.

Theme 5: Wanting to break the glass ceiling

Some feelings of frustration were indicated as a result of a desire to become as fully involved as possible, but there being a limit to involvement. This is summed up by Kimberley: 'I think there is a glass ceiling. I think there is one', and Joy who stated she has 'tried to push it [involvement] to the ceiling'. Frustration was evident by repeated attempts to become more involved:

> …there is meant to be opportunities to teach and I haven't been given that opportunity yet…I've expressed an interest more than a couple of times at doing this type of work, but I've not been able to do it yet, which has been a bit of a bugbear of mine. (*Ross*).

It was implied that the decision-making power ultimately lies with professional course staff:

> …what I would say is that we're very welcome and we are involved and we do all kinds of things, but we're kind of almost…under supervision. (*Kimberley*)

This indicates that service users might not always be treated primarily as colleagues, a factor which was previously identified as important in determining a sense of psychological safety.

Discussion

The research is part of the early literature exploring SUs'/carers' experiences of the personal effects of involvement in clinical psychology training and is the first to do so across multiple programmes[18].

Building a safe foundation for involvement

What appeared to underpin participants' experiences of involvement was their sense of safety which centred around the quality of their relationships with staff and fellow SUs. Aspects of high-quality relationships which facilitate psychological safety in organisations include carrying capacity, tensility, connectivity, mutuality, and positive regard (see Carmeli *et al.,* 2009). How to

[18] See extended paper for further discussion of the results alongside the evidence base and psychological theory and further strengths of the research.

optimise these aspects of high-quality relationships between SUs, staff and trainees warrants further research, particularly considering each group holds distinct roles and the potential tensions within these relationships.

The sense of supportive group dynamics might be understood as related to ideas of universality and group cohesion promoting group development (Yalom and Leszcz, 2005), meaning SUs feel part of an 'in group' (Tajfel and Turner, 1979) likely to be particularly important in fostering safety amongst SUs who may have been marginalised and treated as part of the 'out group' in society. However, transitioning to the 'in group' in involvement might not be as easy as social identity theory proclaims due to SUs being at different stages of recovery and multiple individuals and identities being present. Additionally, power imbalances between new and existing group members were highlighted as barriers to re-orientating to the new group, adding to what is already a stressful process (Iyer *et al.,* 2008). However, overcoming these difficulties can give opportunity to develop socialising techniques (Yalom and Leszcz, 2005), building connections which is an important part of the personal recovery journey (Leamy *et al.,* 2011). Therefore, management of group dynamics by SUs or programme staff might lead to longer-term benefits for SUs. However, management by programme staff has the potential to invoke a power imbalance.

Power, empowerment, and identity

Similar to previous research (Campbell and Wilson, 2017), further challenges centred around power were identified by SUs. Participants initially perceived professional staff to have more 'expert power' (French and Raven, 1959), particularly in activities where there is more responsibility such as at selection. This appears to subside over time when SUs described themselves taking over the 'expert' role, empowering them and contributing towards building a positive identity. SUs and professionals should therefore explore in depth the intricacies and nuances of managing and sharing power.

Feeling valued seemed to be contingent on feeling listened to and staff not exerting expert power (French and Raven, 1959) by overruling SUs and allowing SUs to hold decision-making power (Lukes, 1974). Less value was felt when decisions were already made by professionals, implying that there can be times

where professionals exert non-decision-making power by controlling agendas (Bachrach and Baratz, 1962). This reported power dynamic within clinical psychology training adds to previous findings that almost all involvement can lead to empowerment (Masters *et al.,* 2002) or disempowerment (Felton and Stickley, 2004), but goes further by considering the types of power at play. Findings also suggest that whilst empowerment is a desired outcome of involvement in clinical psychology training (Tambuyzer *et al.,* 2011), SUs do not feel fully empowered. This may be due to the emphasis on clinical psychologists providing the majority of learning opportunities rather than SUs (BPS, 2019). Additionally, course staff and SUs might hold different perspectives on what being fully empowered means (e.g. course staff might perceive that SUs have full empowerment within accreditation and budgetary requirements, whilst SUs desire more). Regardless, SUs not perceiving that they are fully empowered could have implications for SUs who are still in recovery from their difficulties considering empowerment is one of the typical characteristics of personal recovery in mental health (Leamy *et al.,* 2011).

A valued identity has been linked to personal recovery (Slade, 2009; Walsh and Tickle, 2017), thus the provision of equal pay in involvement has the potential to impact a SU's personal recovery as well as building a positive identity. Ensuring equal pay also goes some way to addressing power struggles that can arise between SUs and academics in an educational setting (Lea *et al.,* 2019) by aiming to solidify SUs' 'expert power' (French and Raven, 1959) as equals alongside that of professional staff on the programme. Furthermore, paying SUs is recommended by the HCPC (HCPC, 2017). Therefore, a more standardised system whereby those involved are paid equally across clinical psychology training courses is recommended in earnest. Guidance on this for those organising such systems can be found in previous discussions on recruitment and remuneration (e.g. Haeney *et al.,* 2007).

The benefits of access to new theoretical knowledge via involvement suggests that within some services professionals exert informational power (Raven, 1965) by withholding information. Professionals working in services should be mindful of this finding and consider sharing information which might help SUs to better understand their difficulties. This might also go some way to addressing the

historical profound inequalities of power between SUs and mental health professionals (Felton and Stickley, 2004).

Participants indicated frustration when they could not be involved as much as they would like. The concept of wanting to break the glass ceiling is in line with previous involvement research which suggests that involvement activity falls short of aspirations (Briggs *et al.,* 2017). Requests for involvement were sometimes rejected and there was a sense that professionals ultimately decided how much SUs could be involved supporting findings of Campbell and Wilson (2017). This implies that professionals hold non-decision-making power as they involve SUs but limit their decision-making capacity by preventing involvement in certain areas. Although likely to vary between programmes and 'full' involvement not being defined, this finding would suggest that in terms of levels of involvement (Tew *et al.,* 2004), overall participants described limited or growing involvement in clinical psychology training despite aspects of collaboration and partnership.

The glass ceiling could be raised by ensuring that SU representatives are involved in designing programme modules. Ideally, this would follow recommendations by Tew *et al.* (2004) which suggest that SU perspectives should be treated as equally valid and part of the core agenda. It was not clear from the present study how much SUs are currently involved in module development, with most participants describing involvement activity centred around teaching and interacting with trainees. This warrants further exploration in future research.

Recovery

Many participants described benefits of involvement that tied in with the CHIME framework (Leamy *et al.,* 2011). In addition to the previously discussed experiences around power and empowerment, there was a sense of connection with their SU/carer group. Another example is participants identifying personal growth that arose from involvement leading to an improvement in meaning and quality of life, hope and optimism about the future. Many of these experiences led participants to indicate they had developed a positive sense of identity including overcoming felt stigmas as a result of involvement. Therefore, whilst not

its explicit aim, involvement can offer an opportunity to further develop recovery, sometimes beyond what has been achievable within services.

Limitations and future research

There were no participants no longer involved in clinical psychology training and only two carers (who were also SUs). Future research should aim to address this as their experiences might differ.

Additionally, as the research did not recruit every SU representative or recruit from every programme it is likely that other perspectives might be held by SUs who did not participate. This limits the findings as not being representative of every SU/carer involved in clinical psychology training. It does, however, provide useful guidance to developing involvement so that it is meaningful for the SU[19].

Conclusion

In conclusion, exploring the personal effects of SUI in clinical psychology training has revealed that SUs derive benefits from involvement relating to a greater understanding of themselves and their difficulties; an improvement in mental health and social functioning; feelings of worth, purpose and value; building and enhancing a positive identity and some feelings of empowerment. However, these benefits are contingent on the environment fostering psychological safety, via positive and supportive relationships with trainees and staff and SUs being treated as equal colleagues and financially reimbursed as such. The environment also has the potential to be triggering for SUs and as such support should be available at these times.

Additionally, it is suggested that the building of a positive identity is partly contingent on whether participants felt a sense of value, worth and purpose in their involvement, which was determined by how empowered they felt. Thus, it is suggested that SUs and professionals explicitly discuss the intricacies and nuances of managing and sharing power to increase the opportunity for SUs to feel valued and therefore increase the chances of them reaping the benefits of developing a positive sense of identity. If this can be achieved, it is likely that involvement in clinical psychology training will be beneficial for SUs and may even

[19] See extended paper for further evaluation of the research including implications, strengths and limitations.

help in their continuing personal recovery, alongside the original aim of enhancing the trainees experience and training.

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EXTENDED PAPER

Introduction

The following section provides additional information on service user involvement (SUI), the literature relevant to SUI and additional theoretical information to provide further rationale for the current research.

Service user involvement

Similar to previous literature (Tickle & Braham, 2012), it is acknowledged that the term "service user" can be generalising and de-personalising and can also ignore other aspects of one's identity (McLaughlin, 2009). However, the term "service user" (SU) is used in the present research due to a shared understanding of its meaning and it being the most frequently used terminology in the literature. In the present research, the term "carer" refers to those who undertake unpaid support to family or friends with mental health difficulties. However, throughout the research it is important that homogeneity of involved SUs is not assumed; although individuals share a common experience of being involved in services, this is not the only identity and life experience the person is likely to hold.

Whilst there has been no consensus on a definition of SUI, it has been broadly defined as "decision making and active participation in a range of activities (e.g. planning, evaluation, care, research, training, recruitment) starting from the expertise by experience of the person, in collaboration with and as equal partners of professionals" (Tambuyzer, Pieters & Van Audenhove, 2011, p.142). The term SUI is commonly used in clinical psychology training and thus is used in the present research. However, patient and public involvement (PPI) is the term that is more generally used for involvement in broader health services and research.

The aims and desired outcomes of SUI vary. In the 1980's the SU movement expanded, with this growth and expanded SU voice being facilitated by the political climate and social context (Croft & Beresford, 1992). Political and ideological outcomes include promoting organisational change via social action, whereby ideologies are challenged, and power structures redefined with the view that involvement in services which effect an individual is a fundamental citizenship right (Gordon, 2005). However, it is acknowledged that whilst power

might be given to SUs on one hand, it is also taken away with the other as professionals can invoke treatment orders meaning they always maintain a degree of power (Felton & Stickley, 2004). Additionally, a critical perspective might suggest that the term SUI in itself holds an inherent power imbalance, as services or training programmes involve SUs and therefore hold the power to invite people in.

Another aim of involvement is to improve quality of services and outcomes for SUs, with involvement being linked to better social functioning, improved self-esteem and better quality of life for those using services in which SUs are involved (Simpson & House, 2002). In education, improving quality of services might be achieved by challenging stigma and facilitating learning for professionals who will be in future services (Schneebeli, O'Brien, Lampshire, & Hamer, 2010; Terry, 2012). Whilst the impact of SUI on those involved has been given less focus in the literature, limited empirical evidence suggests benefits for those involved include feeling empowered and valued, whilst also gaining confidence and life skills (Brett et al., 2014).

Considering the above, the desired outcomes of involvement have been summarised as SU empowerment, SU satisfaction, healthcare accessibility, high quality of care and recovery of SUs, with a long-term desired outcome of improving SUs' quality of life (Tambuyzer et al., 2011).

Broadly speaking, the ideology of involvement can take either a consumerist or democratic approach. Beresford (2002) describes a consumerist approach as generally meaning that power and control remain with the institution and involvement centres around efficiency, economy and effectiveness. It might therefore be said that SUs would be involved but have limited power to make any changes. The opposing democratic approach concerns itself with equality and shared power and control, with a focus on inclusion, autonomy and independence (Beresford, 2002). Therefore, in a democratic approach, SUs would likely be involved in decision-making and deciding on content of services or education they are involved with.

In attempts to measure and locate the level of SUI, a five-stage model adapted from Arnstein's Ladder of Citizen Participation (1969) was developed

by Tew, Gel and Foster (2004) and termed the Ladder of Involvement, with the higher the level the greater the involvement. A critique of the ladder is it is only interested in outcomes rather than processes of involvement. Therefore, Tritter and McCallum (2006) suggest a mosaic is a better analogy to understand involvement which can better represent the complex and dynamic relationships between individuals, communities, organisations and the healthcare system – all of which successful involvement depends upon.

One way of considering involvement is thinking about the levels at which it occurs within mental health care (Tambuyzer et al., 2011). Micro level involvement concerns being involved at the individual level (e.g. regarding their own care plan or treatment choice). The second level, meso level involvement, concerns having representation in a healthcare service (e.g. on a board of advisors). The third level, macro level of involvement, concerns being involved in the development of mental health policy. Finally, Tambuyzer et al. (2011) propose that meta-level involvement concerns involvement in research and in the education of healthcare professionals.

Involvement in the training of healthcare professionals

The level of involvement in the training of healthcare professionals varies, with some training programmes offering SUs academic positions whilst others have more limited involvement such as involvement in teaching discussions or providing feedback (Happell et al., 2014). There is general agreement that involving SUs/carers in the training of healthcare professionals is beneficial for trainees. For many years much of the literature focussed on how involvement impacted on trainees' learning and future practice. For example, although not a causal relationship, McCusker, MacIntyre, Stewart and Jackson (2012) found that teaching provided by SUs/carers was associated with trainee mental health social workers having increased confidence in interacting with SUs. Additionally, Blackhall, Schafer, Kent and Nightingale (2012) suggest that SUI meant that trainee nurses' preconceptions were challenged, and they developed more positive attitudes and increased empathy towards those with mental health difficulties. Other found benefits to trainees include improved communication skills (Repper & Breeze, 2007), development of their learning (Clarke & Holttum, 2013), and the provision of a different

perspective (Harper, Goodbody & Steen, 2003). SU/carer involvement in education of healthcare professionals is therefore highly advocated.

Research has also focused on how to make SU contributions more meaningful, for example via the production of DVDs by SUs to enable trainees to develop a formulation (Tickle & Braham, 2012). However, such research tends to focus on how to make learning more meaningful for the trainee rather than optimising the experience for SU/carer representatives. The lack of prioritisation of SU considerations by the researchers is perhaps reflective of where the power lies within the research and education system. This seems to be a theme throughout involvement in mental health education literature across professions, with a systematic review identifying that SUs' experiences are under-represented, with only six out of 30 reviewed papers containing a SU perspective (Happell et al., 2014). This suggests that consideration of the personal impact on SUs involved in training is under-represented across professions.

One study which did explore SU perspectives was conducted by Rhodes et al. (2014), who explored SU/carer's experiences of being involved in healthcare education and how this impacted on their health and wellbeing. Participants mostly consisted of those with physical health difficulties. Findings highlighted increased confidence and self-esteem and better management of long-term conditions arising from involvement. However, the research was conducted by the participants themselves due to the positive experiences they had had with involvement and this may bias the results somewhat. To build upon this research it would seem prudent to focus on the personal impact of involvement more broadly to account for factors alongside health and wellbeing such as identity. It might also be argued that the personal effects of involvement may differ for those with mental health difficulties compared to physical health difficulties, meaning it would be useful to explore psychological processes through which benefits or less positive outcomes operate for SUs who are involved in education of mental health professionals, an area which is under researched at present.

Involvement in clinical psychology training

At the time of the current research, all UK Clinical Psychology Doctorate courses had SU and carer involvement, a requirement by both the British Psychological Society (BPS, 2019) and Health and Care Professions Council (HCPC, 2017). SU and carer representatives' roles vary between course programmes and between SUs. SUI can include being involved in selection and recruitment of trainees, planning the curriculum, research, participating, and leading teaching sessions and sharing experiences. The role therefore remains broad and relatively undefined with an overarching aim of optimising the training of future Clinical Psychologists. However, the flexibility of the role also allows the opportunity for it to be developed locally and organically in a way that SUs want and can achieve, thus preventing SUs having to fit into specific agendas.

SU/carer accounts of being involved in one clinical psychology training programme were reviewed by Holttum, Lea, Morris, Riley and Byrne (2011). They concluded that although there are clear benefits to SUI for trainees, involvement can also have a personal impact on SUs, who initially found it daunting becoming involved in an educational setting such as a university. The researchers outline the need to renegotiate roles so that SU/carer representatives are also seen as expert colleagues and trainers, and highlight the point made by Bates (2011) that for this to happen professionals may need to allow themselves to feel uncomfortable; this is likely due to a shift in power. It might also be said that renegotiation of roles involves appropriate and adequate payment of SUs in line with their professional colleagues, a factor which equates with value (Breeze & Repper, 2007).

Perceptions of the objectives and potential outcomes of SUI in clinical psychology training have been investigated through focus groups with SUs, training staff and trainees (Lea, Holttum, Cooke & Riley, 2016). A thematic analysis revealed a common theme of importance regarding SUI across groups was "being/staying human". Considering previous literature which found stigmatising attitudes were potentially reinforced by SUI in psychiatry (Gordon, Huthwaite, Short & Ellis, 2014), the results highlight the importance of SU/carer representatives still being seen as human in attempts to reduce this stigma. All

of these concepts likely link into one's identity and would warrant further exploration.

A case study by Lea et al. (2019) highlighted that SU/carer involvement on one clinical psychology training programme aims to ensure that trainees see SUs/carers as humans first, with an aim of breaking down negative stereotypes of those with mental health difficulties (Corrigan & Shapiro, 2010). They highlight difficulties with co-production in Universities which are hierarchical and primarily value academic qualifications. On their particular programme, Lea et al. (2019) state that a slow process of breaking down stereotypical roles (SU/carer, service provider) has taken place with an aim of achieving more co-production. However, SUs spoken to in the research indicated that there can be a power struggle between themselves and academics. Lea et al. (2019) also quote SU/carer representatives who indicated that they feel valued and heard via their involvement. However, a weakness of this study is that the research and interviews appear to have been carried out by the SU/carer co-ordinator and it is possible that social desirability may have played a role in interviewees responses. Similarly, due to the researcher's dual role, it may have been difficult to maintain an objective stance. Additionally, the sample was from one training programme which had significantly advanced its involvement (e.g. including assessing students). It would therefore seem prudent to carry out further exploration of involvement experiences on other training programmes whereby involvement might be less extensive.

To explore SU experiences of involvement in clinical psychology training, an interpretative phenomenological analysis (IPA) of data gathered in semi-structured interviews revealed themes relating to group processes, advocating, transforming and power and captured personal, professional and group experiences (Campbell & Wilson, 2017). The group processes were similar to the therapeutic processes outlined by Yalom and Leszcz (2005), therefore indicating that SUI may lead to positive change for participants. Furthermore, the limited decision-making capacity of the group was highlighted as potentially preventing progression from tokenistic to more progressive involvement. In addition, Campbell and Wilson (2017) found paradoxical positions regarding power. They suggest participants felt powerful in relation to their sense of self

by positively shaping future psychologists and making a difference to mental health services and therefore SUs. However, a sense of powerlessness of self was also highlighted in relation to restricted access to trainees which in turn led to a sense of invalidation. This is in line with findings by McCusker et al. (2012) who found that whilst SUs were participating in education of professionals, they still experienced a lack of control over factors relating to the course. Whilst the research by Campbell and Wilson (2017) was one of the first to explore experiences of SUI in clinical psychology training with a rigorous methodology, their sample size of five participants from one training programme might mean that transferability of findings is very limited and findings could reflect the workings of one particular programme. The findings of this study might therefore be built upon by exploring experiences of SUs from multiple course programmes to reflect different kinds of involvement experiences. It might also be said that research taking a deductive approach to further explore personal effects of involvement may allow further exploration of ideas related to transformation and power. Additionally, views of SUs no longer involved in clinical psychology training were not considered and it is possible that their experiences may have differed.

Considering involvement is in an educational setting, it might be argued that any benefits to SUs found in the involvement literature are contingent on a psychologically safe workplace being created through the development of quality relationships (Carmeli *et al.,* 2009) thus minimising interpersonal fear (Edmondson, 2018), but this is yet to be explored empirically in the involvement literature.

Psychological theory related to SUI

The following theories offer context to the design of the present study and the construction of themes.

Power and empowerment. It is argued that empowerment is a personal process and is defined by the World Health Organisation (WHO, 2010) as referring “to the level of choice, influence and control that users (...) can exercise over events in their lives*”.* Therefore, to be empowered, the notion of power should also be considered. The literature suggests that almost all

involvement can lead to empowerment (Masters et al., 2002; Simpson & House, 2003) or disempowerment (Felton & Stickley, 2004); and it can therefore be assumed that empowerment might be a key part of the personal experience of SU/carers involved in clinical psychology training, assuming the right kind of environment has been created for this.

Aspects of the involvement movement are centred around attempts of SUs and carers to reclaim power from stakeholders traditionally seen as holding more power (e.g. professionals), particularly in light of historical profound inequalities of power between SUs and mental health professionals (Felton & Stickley, 2004) . SUI in education consists of different stakeholders coming together, and issues with power struggles between SUs and academics involved in clinical psychology training are still prevalent (Campbell & Wilson, 2017; Lea et al., 2019). With this in mind as well as service user empowerment being a desired outcome of involvement (Tambuyzer et al., 2011), theories of power should be prominent when considering SUI, and in this case the experiences of the personal effects of involvement in Clinical Psychology training whereby the university setting is traditionally hierarchical and primarily values academic qualifications (Lea et al., 2019) and therefore arguably power is traditionally held within the educational system.

Lukes (1974) originally defined power as one person exercising power over another to affect the other person in a manner which is contrary to their interests. Whilst this definition is rather simplistic and generic, it provided the platform for Lukes (1974) to construct a three-dimensional account of power to expand upon his original definition. The first dimension (decision-making power) proposes that the person who prevails in a decision-making process whereby there is a conflict of interest holds the power as they are able to modify the behaviour of others. The second dimension (non decision-making power) was brought about by Bachrach and Baratz (1962) arguing that a person or group holds power if they consciously or unconsciously shape an agenda which limits decision making. The first two dimensions therefore conceptualise power when there is a conflict regarding a decision. The third dimension (ideological power) goes further and states that rather than arising from conflict, power is exerted when a person or people willingly act in ways which appear against their own

interests as a result of a pervasive system of ideology being created by the powerful. The system therefore serves to ensure that the powerless behave as the powerful wish without exerting coercion or forcible constraint.

Since Lukes proposed his theory, critics have argued that the theory does not account for the social mechanisms which allow power to operate (e.g. the social features which allow an individual or group to exercise power over others) (Little, 2010). Additionally, it has been argued that in relation to ideological power, a person's willingness to act in a certain way may actually be as a result of their own values and thus Lukes' theory may be condescending towards those who do not share the same values as Lukes (Benton, 1981; Clegg, 1989; Hay, 1997). However, counterarguments suggest that this view might deny any sort of normative social analysis, and that people may not actually always be the best judge of their own interests (Dowding, 2006), therefore suggesting that individuals such as Lukes can and should analyse and evaluate others' situations.

Understanding SUs' experience of the decision-making process around the amount and type of involvement activity and applying Lukes' theory might help make links between types of power being exerted and how this impacts on SUs. However, whilst Lukes' (1974) dimensions offer useful conceptualisations of power, the theory appears to offer little insight into factors which enable an individual or group to influence others and therefore exert power over them. It is therefore also pertinent to consider power theories which account for mechanisms of power which might be applied when understanding involvement experiences, one of which is the bases of social power.

By considering the ability of a power figure to use resources available to them to bring about change in another person, an initial five bases of social power were proposed by French and Raven (1959). These are; a) reward power – the perception that others are in a position to offer a reward; b) coercive power – the perception that another can punish for noncompliance; c) legitimate power – the perception that a person has the legitimate right to exert power due to their appointed or elected position; d) referent power – based on identifying with somebody due to their likeability and charisma; e) expert power

– perceiving that another person has special knowledge or expertise. A sixth base was added later (Raven, 1965), informational power – a person being in a position to share, withhold, distort, manipulate, or conceal information. This theory offers more insight into the underlying mechanisms of power and therefore considering both theories together would likely offer insight into conceptualisations of power in terms of decision-making as well as factors which enable this power.

The five bases of social power have been wide reaching, with it being the most frequently utilised model of social power in the decades since French and Raven first introduced the theory (Northouse, 2007). Whilst further theories and taxonomies of power have been developed since the five bases of social power were introduced, many of these theories have their roots in or have much in common with French and Raven's original ideas (Elias, 2008), suggesting that many of them still remain relevant in explaining power. For example, Morgan (2007) distinguished sources of power, one of which was the control and distortion of information, which could arguably be mapped onto informational power suggested by Raven (1965). There have however been some more recent developments and expansions on French and Raven's theory, for example the role that gender might play on one's ability to exert social power (Elias, 2004; Elias & Cropanzano, 2006; Elias & Loomis, 2004).

As both theories of power discussed have not yet been considered in research exploring SUI in the education of trainee Clinical Psychologists, it would be pertinent to explore whether and how any of the dimensions and/or bases of power are experienced by those partaking in involvement and conversely whether they feel empowered to be able to exert any of the dimensions and/or bases of power in their involvement activity (for example, whether they can exert their expert power which comes as a result of being an expert by experience) and whether programmes allow this. This would seem important in considering whether SUs are truly able to reclaim power within an educational setting, or whether they are constricted from doing so by the power bases operating within the university.

Recovery. Alongside an increase in SUI in mental health practitioner training, there has recently been a more recovery-oriented approach to mental health care. Additionally, recovery has been identified as a desired outcome of involvement (Tambuyzer et al., 2011). Whilst the clinical definition of recovery often centres on curing or reducing symptoms (Slade et al., 2014), personal recovery is a subjective experience (Bellack & Drapalski, 2012) focusing on one's journey towards living a valued and meaningful life (Slade, 2009). An individual can experience both clinical and personal recovery, or one without the other (Slade et al., 2014). It is highly possible that SU representatives may have experienced or still be experiencing a sense of personal and/or clinical recovery from their difficulties. It therefore seems prudent to consider the role of recovery and how this might impact on SUI or conversely how SUI might impact on recovery.

It is argued that the typical characteristics of the recovery journey in mental health identified in the CHIME framework (Leamy, Bird, Le Boutillier, Williams & Slade, 2011) moves to add clarity to the concept of recovery which has previously lacked definition in the literature. This theory will be considered when interpreting the results of the current study to determine whether any of these elements are present in participants' involvement work. However, it should be noted that one of the most common characteristics in the recovery journey identified in papers reviewed by Leamy et al. (2011) was "individual and unique process". Therefore, whilst the CHIME framework informs aspects of the design and data analysis of the current research, individual experience and meaning being attributed to recovery which does not fit in with the CHIME framework will not be discounted.

Since the introduction of the CHIME framework, its validity as a way of measuring recovery has been tested. For example, Bird et al. (2014) facilitated focus groups containing mental health SUs and based on a thematic analysis of the data concluded that participants' meaning and experience of personal recovery tied in with the CHIME framework. This suggests that the CHIME framework provides a defensible theoretical base for recovery in clinical and research purposes. Similar findings with regards to validity of the CHIME framework have been found in international systematic reviews (Slade et al.,

2012). However, despite the apparent validity of the CHIME framework as a way of considering recovery, it should be noted that even in studies whereby the CHIME framework was supported, areas of difference to the framework were still found when considering recovery (Bird et al., 2014), further demonstrating the importance of not discounting data which participants might subjectively consider to be part of their recovery. Nonetheless, despite difficulties conceptualising recovery, the CHIME framework is still considered one of the prominent ways of considering personal recovery, with the most recent studies using the CHIME framework when evaluating psychometric properties of measures of recovery (Penas et al., 2020).

Research into SUI in mental health services found that participants explicitly linked experiences of SUI at a meso level (e.g. meaningful role, valued identity and sense of empowerment) with their own definition of recovery (Walsh & Tickle, 2017). Whilst this suggests that SUI in mental health services may promote personal recovery, little is known about whether this is also the case for SUs involved in mental health education programmes.

Identity. In involvement, being seen as human helps to reduce stigma (Lea et al., 2019). Therefore, when considering the personal effects of SUI it also makes sense to consider how involvement might impact on one's sense of who they are - their identity. Although initially sought for their SU identity, in joining a staff team in involvement in clinical psychology training SUs are also offered and may assume further identities (e.g. teacher/colleague/peer/staff). The CHIME framework highlights identity as a prominent aspect in the personal recovery in mental health literature, specifically relating to dimensions of identity, rebuilding/redefining a positive sense of identity and overcoming stigma (Leamy et al., 2011).

Several challenges to building a positive identity in SUI in mental health services have been identified (Tse, Cheung, Kan, Ng & Yau, 2012). The first concerns perceptions of others towards the SU group. If those within the group are seen primarily as having mental health difficulties as opposed to being seen for their strengths, then this can be a barrier to identification with the group. The second challenge concerns shifting from the majority group of healthy

individuals to the minority group of those who are “unwell” and thus less powerful. In the case of SUI in education, the second challenge might actually be reversed, as one moves from identifying with a minority group of unwell individuals to a more powerful majority position within an educational setting. The third challenge concerns re-orientating themselves with the new group which can be associated with stress (Haslam, Jetten, Postmes & Haslam, 2009). Whilst a shift in identity has the potential to be empowering for the individual in SUI, the stress which arises as a result in the shift in identity might also negatively impact on mental health. Tse et al.’s (2012) study was conducted in Hong Kong and so it would be interesting to explore whether such challenges also exist in more western cultures and in involvement in education.

All of the above challenges to building a positive identity might better be understood by the application of Tajfel and Turner’s (1979) social identity theory which proposes one’s identity is grounded in the group to which they belong and thus they may exaggerate similarities within this group (the “in group”) and differences between other groups (“out groups”) to enhance their identity. Furthermore, social identity is seen as “fluid” (Haslam *et al.*, 2009), with self-perceptions changing depending on the social group one identifies with.

Social identity theory has been explored empirically and has been found to be a capable way of robustly explaining group behaviour in both laboratory and field settings (Abrams & Hogg, 1990). However, whilst it might explain behaviour, critics have highlighted that the theory makes it difficult to predict future behaviour (Korte, 2007). Additionally, what the theory perhaps originally lacked was detail on the process of transitioning from an individual identity to a group identity, with more recent research focusing on this and finding that individuals alter their personal behaviour to fit in with values and norms of the group (Turner & Onorato, 1999). Further research into the theory has also suggested that group identity is more powerful than individual identity (Hogg & McGarty, 1990), thus group membership in SUI might be particularly important for SUs who want to reclaim power. Indeed, it has been suggested that social identity can foster competition between groups, particularly concerning power, status and superiority (Abrams & Hogg, 1990). Despite social identity theory originating in the 1970’s, it is still widely applied in the literature, for example

when considering group processes in medical education (Burford, 2012) and the professional identity of nurses (Willetts & Clarke, 2013).

In SUI in education, as well as belonging to the SU group, SU representatives may also identify as being part of the wider group of educators within the university setting. However, this might be contingent on them being able to exert their expert power as SUs in order to be able to hold decision making power. These factors combined have yet to be explored empirically in research concerning SUI in education and so would warrant further exploration.

Group development. As was previously highlighted in the literature (Campbell & Wilson, 2017), one might expect that involvement in clinical psychology training would elicit some of Yalom's processes of group development, namely universality, altruism, imparting information, the development of interpersonal skills and group cohesion (Yalom & Leszcz, 2005). It would therefore make sense to further explore these and other factors of group development in the current research which would move beyond previous literature by considering these factors in the research design and applying them to a wider sample from multiple programmes.

Yalom's processes of group development continue to be empirically evaluated in group settings, with the focus being on psychotherapy groups. This has helped increase understanding of which factors are important in various groups. Self-report measures have found cohesion to be the central therapeutic factor which facilitates the other factors (Bernard et al., 2008). However, the interplay between and value placed on each factor can vary depending on the group, with one study identifying 'cohesion', 'universality' and 'instillation of hope' as being the most valued factors for adolescents (Chase, 1991), whilst those with personality disorder valued 'cohesion' considerably less (Sayin et al., 2008). A relationship has also been found between presence of Yalom's factors and the resolution of psychological distress (Hauber, Boon & Vermeiren, 2019), however causation cannot be assumed. Most studies use Yalom's questionnaire to rank therapeutic factors, which it might be argued excludes other therapeutic factors that may be important in a group setting. Additionally, very little literature exists evaluating Yalom's stages outside of a therapeutic

setting, although recent research has suggested that some of the factors might be present in SU groups involved in clinical psychology training (Campbell & Wilson, 2017). Thus, this warrants more research which might expand the application of the theory.

Rationale for current research

To further explore themes derived in studies to date and to enable application of relevant psychological theory, a more rigorous method of data analysis is needed. The deductive nature of the current research will allow the personal effects of involvement to be better understood by analysing through a lens of psychological theory relating to identity, power, recovery and group development and will move beyond analysing experiences which might be reflective of how a particular programme is set up. Gaining SU perspectives is also particularly important in expanding the literature, as SU perspectives have previously been neglected in involvement in education research (Happell et al., 2014).

Project aims

The aim of this research was to explore service users'/carers' experiences of the personal effects of involvement in clinical psychology training. It sought answer to the question: What are service users'/carers' experiences of the personal effects of involvement in clinical psychology training? The specific objectives of this research project were to use a qualitative approach to explore the experiences of service user/carer representatives involved in clinical psychology training and to use psychological theory to develop an understanding of the personal effects of involvement.

The terminology of 'personal effects' aimed to incorporate exploration of psychological concepts including (but not limited to) self-esteem, self-concept, self-perception and mental health, and whether SUI effects these concepts either positively or negatively.

Methods

This section provides additional detail regarding epistemological stance, reflexivity and the choice of methodology. It also offers further information on participants including inclusion and exclusion criteria and recruitment procedure, details of ethical considerations, further information on data collection and the development of the semi-structured interview schedule and details of the quality analysis of the research.

Epistemological stance

The researcher took a critical realist epistemological stance. It was assumed that data informs us about a reality, without being a direct mirroring of reality (Harper, 2011). Thus, other evidence needs to be drawn upon (e.g. theory) to explain the driving and maintaining factors of the reality (Willig, 2012). The researcher's viewpoint is that involvement in clinical psychology training is a reality that exists, but that individuals will have their own take on involvement. The researcher therefore accesses information and knowledge about involvement through participants' perceptions of it.

Reflexivity

As well as the aspects of reflexivity discussed in the journal paper, the researcher held a shared language (clinical psychology) that SUs/carers were aware of which may have influenced how they spoke about particular experiences.

In addition, the researcher had an existing relationship with four of the participants as they were involved SUs on the clinical psychology training programme that the researcher was training on.

Rationale for qualitative methodology

The exploratory nature of the research with a focus on experience makes a qualitative methodology appropriate. This is due to the interest in individual meaning and seeing experience in context, as opposed to seeking to test hypotheses by controlling variables and identifying relationships between variables or gathering numerical data which would be more suited to a quantitative methodology (see Braun & Clarke, 2013, for more).

Choosing a qualitative methodology

In considering the best way to address the research question, several qualitative methodologies were considered. The researcher used their familiarity with each approach to select the most appropriate method (Starks & Trinidad, 2007). These are outlined below along with a rationale as to why they were not used. A rationale is then provided for using thematic analysis.

Grounded theory (GT). GT aims to construct a theory based on data (Charmaz & Henwood, 2008). As in other qualitative methods, interview is a key method of data collection. In GT the researcher takes an inductive approach and builds a theoretical analysis based on interpretations from each interview. Thus, the researcher might alter the interview schedule as the research progresses and more participants are interviewed in order to further pursue strands which are arising from the data. In GT, the researcher does not review the literature before data collection in order to disengage from their own perceptions and maintain independence from the data.

In the present study, the researcher had already reviewed relevant literature and theory relating to SUI prior to commencing with the research, meaning it would not have been possible to maintain independence from the data. Indeed, the research was interested in taking a deductive approach to explore SUs' experience of the personal effects of involvement in clinical psychology training which required reading of the literature and relevant theory in advance. Thus, the aim was not to construct a theory from the data. Therefore, GT was not a suitable approach to address the current research aims.

Discourse analysis (DA). DA is concerned with the construction and function of language and takes the view that rather than representing reality, language actually constructs it (Georgaca & Avdi, 2012). DA therefore fundamentally holds a socially constructionist epistemological stance. Rather than being concerned with the meaning of what a participant says and what this might say about the reality of their experience, a DA approach attempts to examine how participants use language to construct that reality and experience within a specific context (i.e. through social or interpersonal processes).

Considering the aims of the present study (to examine personal experiences rather than the discourse or construction of those experiences) and considering the researcher's critical realist epistemological stance being at odds with the social constructionist stance of DA, DA was not considered a suitable approach.

Interpretative phenomenological analysis (IPA). As well as being concerned with experience, IPA focuses on the meanings that individuals attach to their experience and how they make sense of it (Smith, 2011). Smith (2011) describes IPA as being subject to double hermeneutic – that is an acknowledgement that the researcher is trying to make sense of a participant making sense of their experience. IPA is therefore open with the concept that the researcher's stance, interests and experience will subsequently influence the analysis. Analysis in IPA is an intense process whereby the researcher tries to stay close to the participant's account whilst also maintaining an outsider stance and asking why participants might be making sense of experiences in a particular way. IPA is also concerned with unique characteristics of participants as well as patterns of meanings across participants. As such, focus of analysis is on developing codes and themes for each data item in turn. Due to the intensity of analysis, IPA is usually conducted with relatively small and homogeneous sample sizes, with samples of between four and six participants common (Braun & Clarke, 2013).

Although the critical realist epistemological stance of IPA fits in with the researcher's stance, the focus on a small homogeneous sample size to allow for a thorough enough analysis meant that the approach was not suitable for the current research. Previous studies in the area had already used small sample sizes and the present research aimed to move beyond this by considering a larger sample size that was more heterogeneous in terms of recruiting participants from multiple clinical psychology courses and capture patterned meanings across the dataset so that experiences were more representative of involvement in clinical psychology training in general as opposed to reflective of one particular course programme.

Thematic analysis (TA). TA was chosen for use in the present research based on the principles suggested by Braun and Clarke (2006) and the aim of analysing a broad data set from a larger sample recruited from multiple programmes. Unlike other approaches discussed above, TA is unique in that it provides a method for data analysis without being prescriptive in terms of data collection, theoretical or epistemological positions. TA is therefore an approach which can span across theoretical and epistemological stances (Braun & Clarke, 2006), therefore TA can be located within the researcher's critical realist stance (Harper, 2011). Thus, TA is a flexible approach capable of delivering a detailed, rich and complex account of data for almost any qualitative research question (Braun & Clarke, 2013) - in this instance it would seem appropriate to address SU/carers' experiences of the personal effects of involvement in clinical psychology training. TA allows for identification, analysis and reporting of themes within data by identifying and analysing patterns within the data set. There are no rigid rules for theme development, with Braun and Clarke (2006) advising against solely relying on prevalence across the data set, and instead suggest focusing on whether that particular theme captures something important in relation to the research question and previous literature/theory.

In TA, there are two primary ways in which themes or patterns in data can be identified, inductively or deductively. In an inductive analysis, themes develop which are strongly linked to the data themselves (Patton, 1990). Therefore, the researcher does not try to fit data into a particular theoretical interest, meaning analysis is data driven. In contrast, a deductive analysis is more analyst driven, meaning the analysis may be driven by the researcher's theoretical or analytic interest (Braun & Clarke, 2006). A deductive approach to TA therefore seemed useful for the present research, with theoretical propositions informing the analysis, with a specific focus on theories relating to potential personal effects of SUI (e.g. power, identity, recovery, group development). However, data that contradicted theoretically driven expectations were still included and specifically analysed, which TA allows for.

Research using TA can be perceived as being overly descriptive of what participants report as opposed to being interpretative in nature (Braun & Clarke, 2013). The present research aimed to guard against this by using a deductive

approach and therefore considering theoretical knowledge throughout the analysis to add further interpretations to what participants were reporting. It might also be said that contradictions made by particular participants are picked up better in approaches which specifically focus on analysing each data item in turn (e.g. IPA), whereas TA's approach of focusing on patterns across datasets might mean that some participants voices get lost. To reduce the chances of this happening, the researcher used coloured text to represent each participant's codes when developing themes which gave an insight into how much each participant's voice was represented within the themes.

Finally, TA has been described as being an accessible method of qualitative analysis (Braun & Clarke, 2013). This was particularly important in the current research when considering that one of the researcher's supervisors was a SU representative. As the aim was for the SU representative supervisor to assist with data analysis, the accessibility of TA was an important factor when selecting the TA approach as opposed to a more complex method such as IPA.

Participants

Sample size. In qualitative research, there is no set standard to compute a sample size (Malterud, Siersma, & Guassora, 2015). Therefore, when determining a target sample size it can be useful to review previous research in the area to estimate the number of participants needed to be able to complete a useful analysis. The present research used data saturation to determine when to discontinue recruitment.

The concept of data saturation originated in GT, whilst for TA Braun and Clarke (2006) give very little guidance on this concept. Therefore, to determine the target sample size, the empirical evidence was reviewed to determine a suitable sample size which might enable saturation to be reached. As the current study explored the experiences of the personal effects of involvement, it was interested in a higher-level concept (involvement) as opposed to a lower-level concept (e.g. particular activities within involvement). For such research it has been found that 12 interviews are sufficient to provide all the themes and over 90% of codes in a TA (Ando, Cousins & Young, 2014). Therefore, for the current research there was a target sample size of 10-15 SUs/carers.

The decision to discontinue recruitment was made when it was felt there were no novel findings, thus suggestive of data saturation having been reached. By the fourteenth interview content was relatively similar with no novel findings, suggesting data saturation had been reached. Whilst it is acknowledged that each person's experience is likely to be unique and therefore more novel findings may have been found if a much larger sample size was utilised (Fugard & Potts, 2015), it was determined that the sample size of 14 allowed enough data for a sufficient analysis to be performed to explore themes relating to involvement experience, while ensuring there was not too much data to manage which may have impacted on the thoroughness of the analysis.

Inclusion and exclusion criteria. The following inclusion and exclusion criterion were applied when recruiting participants:

Inclusion criteria:

Male or female SU/carer representatives could participate in the study if:

- They are aged 18 years or over
- They are/were recognised as a service user/carer representative on a UK Doctorate in Clinical Psychology programme
- They have been/were a representative for at least 6 months (to allow for sufficient reflection on experiences)

Exclusion criteria:

- Those who cannot give informed consent to take part in the research (with the researcher using Trust training on the Mental Capacity Act 2007 to inform this decision)
- Those who cannot verbally communicate fluently in English

Ethical considerations

As sponsor for the research, ethical approval was granted by University of Nottingham's The Division of Psychiatry & Applied Psychology (DPAP) research ethics sub-committee (Appendix E) on 20th November 2019. An amendment was submitted in January 2020 and subsequently approved on 14th February 2020. The amendments consisted of the following:

1. Offering Skype as an option for the interviews (alongside the already approved face-to-face and telephone options) to increase accessibility. This is because some potential participants requested a Skype interview as opposed to telephone or face-to-face. Despite this amendment, those requesting a Skype interview did not get back into contact meaning no Skype interviews were conducted.

2. Inclusion of a phone number for interested participants to contact the researcher on in the recruitment advertisement/email to organisations as some gatekeepers informed the researcher that some SU/carer representatives did not use email. This phone number was used for research activities only and was not the researcher's personal phone number.

3. Allowing participants to send their completed consent form to the researcher in the post if they do not have email access.

4. Including the possibility to conduct face-to-face interviews at the University the SU/carer representative is affiliated with (as a last resort). This was to increase accessibility. This was due to a request of a potential participant who was unable to travel to University of Nottingham for a face-to-face interview and did not wish to conduct the interview via telephone or via Skype, but instead requested an interview at the University their course programme was affiliated with. This never happened as by the time the amendment came back the study was fully recruited to.

Risk of harm. It was not expected that there would be any risk of physical or emotional harm from the research study. It was acknowledged that discussing personal effects of involvement might mean discussing a sensitive topic (e.g. mental health). In light of this, the interview questions were worded in a way which allowed participants to control what they wished to share and how in depth they wished to go. Participants were regularly reminded that they could choose how much they shared and if it became too much or invoked anxiety/distress, then they could take a break or move onto the next question. No participants indicated that they felt the interview was distressing and every participant answered every question. Participants were signposted to appropriate support resources via the participant information sheet and also had

the opportunity to talk with the researcher who could signpost further (no participants did this). A debrief was also offered at the end of each interview.

Confidentiality. Participants were informed that their participation in the study and the data they provided would be kept confidential unless they disclosed something which led the researcher to believe that themselves or others were at risk. To protect participants' confidentiality, they were assigned a participant number and a pseudonym which were used when transcribing and analysing the research and when quoting participants in the research report. Any potentially identifiable information was omitted from the results, including the names of third parties which were either omitted or changed.

Information management. Hard copies of data were stored in a secure and locked office. Electronic data was stored on the researcher's password protected drive at the University of Nottingham. In accordance with the University of Nottingham's research code of conduct, all data will be securely stored at University of Nottingham for seven years.

Reimbursement of participants. Participants were offered a £10 multi-store gift card for taking part to compensate them for their time and it was checked that this option was suitable for them (all participants were happy with this choice of gift card). This was offered to show that participants were valued for their time, as appropriate and adequate payment of service users has been equated with value in the involvement literature (Breeze & Repper, 2007) and the study tried to keep to these principles. Although payment of participants is a debated topic which researchers have not reached consensus on (Braun & Clarke, 2013) efforts were made to ensure that payment was not conditional on participants completing the study; therefore if they agreed to take part but later withdrew they would have still been given the gift card so not to coerce them. It was hoped that the multi-store nature of the gift card would mean that participants would have the option of spending it in a store of their choosing. Gift cards were chosen so as not to count towards income and thus affect any benefits participants may have been claiming.

Recruitment procedure. Purposive sampling is commonly employed in qualitative research to enhance understanding of a particular group's

experience, thereby enabling the greatest insight into the research question (Devers & Frankel, 2000). Recruitment took place across multiple programmes to ensure that the findings were not just reflective of involvement in one particular programme, but reflective of involvement in clinical psychology training more broadly. Study information was passed on to SU/carer representatives by course staff who oversaw involvement on their respective programmes and the Group of Trainers in Clinical Psychology Involvement Subgroup mailing list (comprising of UK Doctorate in Clinical Psychology [DClinPsy] course staff and lead SU representatives). This was to enable the potential participants to be approached by somebody they were familiar with and to protect the confidentiality of the SUs/carers by not passing their details onto the researcher without their consent. The gatekeeper email to course staff (Appendix A) emphasised that they should not exert any coercion on people to participate with a view to ensuring participation was entirely voluntary. To guard against “cherry picking” SUs, they were also asked to pass on information to all of their SU/carer representatives. Those who were interested were then asked to contact the researcher directly for further information.

Written informed consent was sought prior to the interview date for telephone interviews or on the day for face-to-face interviews. For telephone interviews participants could either sign and electronically return this form via email or post it to the researcher at University of Nottingham.

Right to withdraw. Participants were informed of their right to withdraw at any point before or during the study without giving a reason. They were informed of this on the participant information sheet and also verbally on the day of interview. Participants were informed that if they withdrew during the study no further data would be collected but information collected up to that date would be kept in the study records and may have still been used in the final study analyses. No participants withdrew from the study.

Data collection

Demographic information. The following demographic information was collected at interview: *age bracket, gender, ethnicity, length of service user involvement, whether they are a service user or carer or both, course affiliated*

with, types of activities involved in, type of mental health service used (including whether they have previously accessed clinical psychology services), years since first use of services, whether they are still using services, years since last service use. The aim was for demographic data to give context to how involvement is experienced at analysis stage; it may be that a certain demographic impacts on the experience and the personal effects of involvement. The demographic data collected was noted and considered when the researcher was making sense of and coding the interview data. However, to protect the identity of participants not all demographic information was reported alongside participant quotes. Where it was felt a participant could be identified from their demographic data, care was taken to not report this. Due to the small but nationally connected involvement community and the involvement of gatekeepers in recruitment, universities are anonymised as A-H and age bracket as opposed to actual age was collected to minimise the chance of participant identification.

Semi-structured interviews. The research used semi-structured interviews to collect data. A semi-structured interview allows for exploration into experience using participants own words, whilst the flexible nature of the interview allows for participants to raise unanticipated issues (Braun & Clarke, 2013). This was therefore a suitable approach for exploring participants' personal experience of involvement in clinical psychology training, and also fits in well with a TA approach. Although the interview was semi-structured with pre-planned questions to keep focus (Appendix F), the researcher regularly checked the interviewees' responses to ensure full understanding, checked inconsistencies in their accounts and encouraged further detail where necessary, as recommended by Coolican (2009), by using probes and asking appropriate follow-up questions.

Question development. In line with the deductive approach to the research, previous theory and empirical evidence relating to SUI was considered when developing the interview questions. In addition, advice was sought from the researcher's SU representative supervisor who read over drafts of questions and made suggestions for changes. These changes centred around encouraging more reflection on emotional and personal impact of

particular experiences which led to the development and revision of questions 6a, 6b, 7a and 7b, as well as specifically probing for questions about how supported one feels which led to the development of question 9 and 9a.

A key part of collecting interview data is to build rapport with the participant (Reinharz, 1993). As such, questions one and two were used as opening questions with an aim of gathering some data but with an overarching aim of easing the participant into the interview and building rapport.

Tajfel and Turner's (1979) social identity theory informed development of questions 3, 3a, 3b, 10 and 10a. Aspects of the CHIME framework (Leamy et al., 2011) informed development of questions 3, 3a, 3b, (identity), 4, 4a, 5, 6, 6a, 6b, 7, 7a, 7b (empowerment) and 9, 9a, 10, 10a (connectedness). Question 10a was also developed by considering Yalom's processes of group development (Yalom and Leszcz, 2005). Ideas around Luke's (1974) dimensions of power and the bases of social power (French & Raven, 1959; Raven, 1965) were explored in involvement via the development of questions 4, 4a and 5.

Data analysis

Braun and Clarke's (2006) six phases were followed to analyse the data. The researcher developed a coding frame which enabled aspects of the theories of interest to be held in mind. The researcher familiarised their self with the data by reading all transcripts and noting down initial ideas which might support or contradict said theories. Initial codes based on interesting features of the data were developed and data was collated relevant to each code. Codes were then collated into potential themes, with data being gathered relevant to each potential theme. Themes were then checked in relation to the coded extracts and the entire data set, with a thematic map being developed (Figure 2).

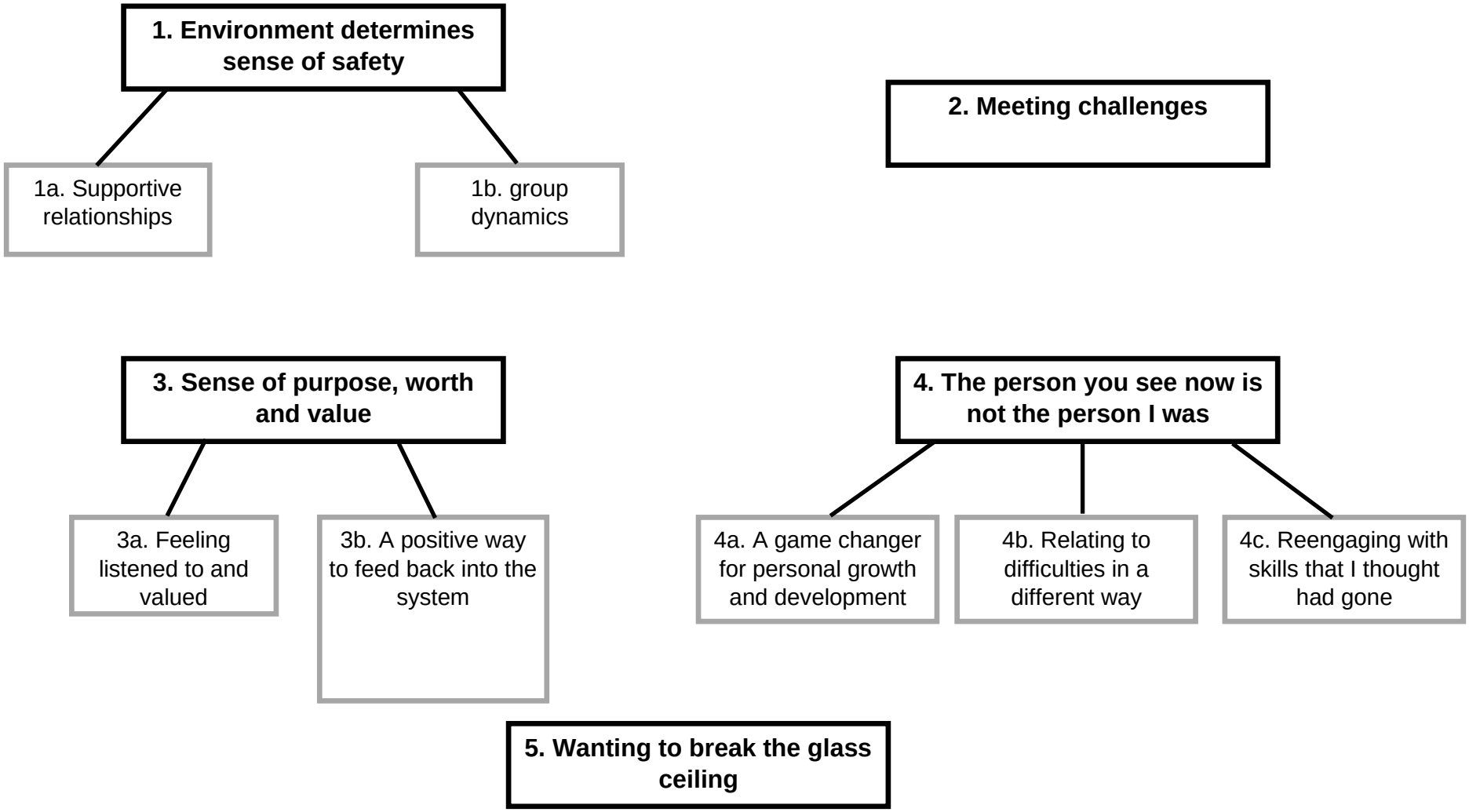


Figure 2. Thematic map

Ongoing analysis took place to refine each theme, with clear definitions and names for each theme being developed (some taken from participant quotations). As suggested by Braun and Clarke (2006), this was not a linear process and instead was more recursive, whereby the researcher moved between phases as needed. Themes were also reviewed and refined by the researcher's supervisors. Theory and existing literature were used to interpret the data (Braun & Clarke, 2006) which allowed for broader meanings and implications to be considered (Patton, 1990). Finally, the report was produced containing extract examples.

To demonstrate attention to trustworthiness at each stage of the analysis, each aspect of the TA conducted in the present research will be considered in the context of the means for establishing trustworthiness of a TA proposed by Nowell, Norris, White and Moules (2017).

In phase one (familiarising self with data) it was ensured that all transcripts were assigned a participant number alongside the corresponding demographic information which enabled demographics to be considered in conjunction with familiarisation. The researcher was already familiar with aspects of the data having conducted the interviews and initial thoughts after each interview were recorded in the researcher's reflexive journal and referring to this also helped with data familiarisation. Repeated reading of the transcribed data alongside listening to the audio recordings all helped the researcher become immersed in the data. Throughout immersion in the data the researcher continued to complete a reflexive diary which enabled their own perspective and existing thoughts and beliefs to be considered, which was particularly important when considering the researcher's values around equality (see reflective section for more detail).

The generation of initial codes in phase two was aided by the use of a coding frame which enabled theories of interest to be kept in mind throughout the analysis, therefore helping to ensure consistency and justification of coding. The researcher worked systematically through the entire dataset to develop and apply codes. Some parts of the data were coded more than once (e.g. to reflect ideas relating to power but also identity). Accounts which contradicted

dominant stories across the dataset or contradicted theories of interest were not discounted and were still coded. Reflexive journaling and meetings with supervisors which were minuted throughout the coding stage provided an audit trail of emerging impressions and how data might relate to each other. Although the primary researcher solely conducted the coding, critically reflecting on and revising the coding with the researcher's secondary supervisor who was less involved with the project as well as using the coding frame enhanced credibility of analysis. The coding frame was also revised in conjunction with the researcher's supervisors when it was felt that the initial coding frame was too broad and not specific enough to involvement.

The third phase consisted of the development of themes after all data had been coded. Although prevalence was considered, this was not the primary marker for whether a theme was developed. Instead, as suggested by Braun and Clarke (2006), a theme was developed when it was considered to answer something important in relation to the overall research question. The deductive nature of the TA meant that themes related to the theories of interest were developed. To organise the data, codes and corresponding data were colour coded to enable visual representation of how many participants contributed towards each theme. Codes which did not obviously fit into any of the initially developed themes and subthemes were held in a "miscellaneous" theme to ensure these were retained for when the themes were revised later in the analysis. Once again, completion of the reflexive journal and minuting meetings held with supervisors throughout the generation of themes enabled an audit trail to be kept.

In phase four, refining themes, visual thematic maps were developed and revised which helped in distinguishing how themes and subthemes linked together, and also led to some themes being merged. The decision to merge some themes and make others subthemes arose as a result of some of the original themes not having enough data to support them and as a result of some themes and subsequent codes centring around the same concepts. After the original themes were developed by the primary researcher, the researcher's supervisor made suggestions for merging and collapsing themes based on her reviewing of the codes and corresponding data under each theme. These

decisions were auditable by the researcher keeping notes of the decisions made and why. As a result of the above process, the number of themes was reduced from an initial nine to five. To test the adequacy of the final themes, the researcher referred back to the raw data to ensure that the themes were grounded in the data and representative of participants' experiences.

In phase five (defining and naming themes) the researcher wrote a detailed analysis for each theme, outlining what story each theme told. The themes were again checked against the data and codes to ensure they were representative. The themes were then ordered to reflect a logical answer to the question of involvement experience (i.e. starting with the environment determining how safe SUs felt at becoming involved, ending with a desire to take involvement further). The organisation of themes was concluded when consensus was reached with the researcher and the researcher's supervisors. Finally, the theme and subtheme names were refined with an aim of ensuring the words of participants were used in the names (e.g. "personal growth and development" became "a game changer for personal growth and development").

Finally, phase six involved producing the report and it was important to use direct quotes within the analytic narrative to help the reader to consider the validity and merit of the themes in relation to the data. To demonstrate that participants were represented across themes, pseudonyms were used. Findings were then considered alongside theory and previous literature in the discussion section.

Coding frame. A coding frame was developed to inform the deductive analysis. The coding frame was developed by considering the key aspects of the theories of interest (Lukes' dimensions of power, French and Raven's bases of social power, the CHIME framework and Yalom's theory of group development) which then allowed the data to be analysed through the lens of these theories.

The a priori coding frame (appendix G) developed by the researcher was broad and considered all aspects of each of the theories of interest However, this was revised in supervision meetings with the researcher's supervisors to be

more concise and focus on aspects of the theories which were thought to be most relevant to SUs involved in clinical psychology training, whilst categorising these to provide an overall concept which captured theories within it (e.g. categories relating to power/empowerment, identity etc). This consensus was reached by discussing existing empirical evidence and which aspects of the theories might relate to involvement experience discussed previously in the literature, as well as considering points of potential interest that the researcher had made notes of in their reflexive journal after conducting the interviews. Thus, the coding frame was revised to include examples of areas specific to involvement whereby aspects of the theories may be relevant. For example, in the original a priori coding frame the idea of expert power was conceptualised as "*Expert – E.g. High level of education/skills/knowledge/experience. People look to you to bring in your expertise and make a decision*", whereas in the final coding frame this was made more specific to involvement in clinical psychology training, "*Exertion of expert power (e.g. are they being looked to for information based on their expertise? Or conversely, does the expert power of the clinical psychologist outweigh the service user power?)*".The final coding frame can be found in appendix H, highlighting which theory corresponds with each aspect of the coding frame.

Quality monitoring

Braun and Clarke (2013) highlight that there are no absolute criteria for monitoring the quality of qualitative research. Whilst one might look to apply principles of reliability and validity to evaluate quantitative research, these concepts are not useful way of evaluating qualitative research for various reasons.

Reliability in research usually means the likelihood of replicating the results when the same measures are administered by different researchers on a different group of participants (Yardley, 2008). In quantitative research, the concept of reliability is important as the aim is to produce generalisable results whilst minimising the influence of the researcher, participants and the context of data collection. Reliability cannot therefore be applied to qualitative research which holds the notion that the researcher does indeed influence the research process and the resulting knowledge produced and does not attempt to

eradicate this. For example, it is acknowledged that when gathering data, the researcher actively engages with the participants (Yardley, 2008) and therefore what is said in an interview will depend on the researcher's presence and skills. Furthermore, the standpoint, theoretical interest, and experience of the researcher will all influence theme development, meaning the same data might be interpreted differently by different researchers (Braun & Clarke, 2013).

Principles of validity are also more suited to quantitative research. Broadly speaking, validity is concerned with whether research shows what it claims to show and includes concepts around whether reality is accurately captured (e.g. construct validity), whether identified effects are as a result of the variable under research or some other confounding variable (e.g. internal validity), whether study results can be generalised to the wider population (e.g. external validity) and whether the research represents the 'real world' (e.g. ecological validity).

These concepts are problematic in qualitative research particularly considering the researcher's critical realist stance which already accepts that a reality is being accessed through people's perceptions and therefore does not seek to directly access the 'reality'. Of most relevance to qualitative research might be ecological validity, as the research does not concern manipulation of variables but instead tries to gather data in the 'real world'. However, it has also been argued that a person is not in their 'real life' in an interview (Fine & Gordon, 1989).

Thus, the traditional concepts of reliability and validity are not appropriate in evaluating the quality of qualitative research as one would not expect the same results to derive from different researchers or from different participants. It might therefore be said that a more useful way of monitoring the quality of qualitative research is to consider reliability more widely in terms of trustworthiness and dependability of the collection and analysis of data (McLeod, 2001). This might be achieved through the use of a quality checklist such as the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018) which considers whether the data was collected in way that

addressed the research issue, whether the relationship between researcher and participants has been adequately considered and the rigour of data analysis.

CASP checklist. The CASP qualitative checklist was utilised to monitor quality throughout the research. This helped to guide the research process, but it should be noted that in completing the checklist the researcher might hold some bias in how much their research reflects the quality criteria.

Research journal. A research journal was kept throughout the research process. This enabled reflection on the researcher's role and particular consideration was given to how and why the researcher might have followed up certain questions with participants, as well as how the researcher related to participants and their experiences (including acknowledging the researcher's own dual role). The journal was also completed during analysis stage (see critical reflection section for more details).

Supervision. The researcher made use of supervision with two academic supervisors, in addition to some supervision from a SU representative affiliated with the same course who helped with developing the questions for the semi-structured interview. It was intended that the SU supervisor would also be involved in the data analysis however timescales meant she was unfortunately not available for this.

Supervision with academic supervisors was used to critically reflect on the themes and sub-themes developed and to make revisions to them based on data the researcher might have overlooked.

Results

This section describes themes and subthemes in further detail and uses additional illustrative quotes from participants that were not included in the main journal paper. Names have been changed to protect confidentiality.

Theme 1: Environment determines sense of safety

Subtheme 1a: Supportive relationships. Seven participants valued the relationship they built with trainees and spoke positively about building connections with them. This was in relation to being part of the "process that trainees go through" (*Jamie*) and feelings of mutual connection as a result; "So

I'd kind of seen them through from first year to third year. So I felt more connected to them and I think they felt more connected to me as well" (*Abigail*). This led to one participant to reflect; "Stop calling yourself trainees. You're actually amazing human beings". (*Jamie*).

Relationships with staff were also key in determining individuals' sense of safety. Some participants reported how they valued emotional support from staff when it was required; "Not just, 'right well I think you should go home then Jamie'. Or big hoo ha, Jamie's come in with a problem. Let's stop the afternoon. It was like, proper caring questions". (*Jamie*).

Other participants valued practical support; "they will explain anything to you that may out of your knowledge bank" *(Sheena)*; "I've always had to claim expenses for getting up there and that side of things is well administered" *(Ross)* and appreciated the small gestures; "there's tea and coffee" *(Emma)*; "some of the staff go and get others lunch or a brew or something like that" *(Ross)*. One participant reflected on how the smallest of gestures can make a difference; "It seems really trivial but it's not. That one little lunch voucher makes such a massive difference, can make such a massive difference to my day". (*Jamie*).

For one participant, support even extended to when staff were not working, adding to their sense of safety; "She's the sort of person that she has no problem whatsoever answering an e-mail on any other day…. if I ask her something or responded to something, I could get immediate support" (*Joy*).

All of this led one participant to reflect that; "I feel very, I feel safe. I do feel very safe in this environment and with the support that we have and the safety net we've got there, definitely". (*Dawn*).

This safe, consistent environment where one knows what to expect is important for those with mental health difficulties; "I mean every meeting is different because of the content, but the environment feels the same. And I think, I think for someone with mental health problems, that's, that's important. That's reassuring". (*Emma*).

A further reflection was around SU not seeking mental health support from staff:

> I think you're there for different reasons, you're not there for your mental health. If that makes sense, you're there to help, you're there to use your mental health experiences to shape clinical psychology, but not necessarily for them to support you in any way. (*Abigail*).

Being treated as an equal member of staff was important to participants; “And it's good because the staff do treat us as members of staff, you know, we're not treated as ‘them’ at all, and that really, that really helps ease the anxiety down, definitely”. (*Dawn*).

Some participants also identified that the environment can be triggering and desired more support at those times. There was a sense that perhaps teaching staff could be more aware of how a triggering environment might impact on SUs:

> And it's one of my trigger points basically and then she showed a video of like an example which had my former psychologist in and again it was like just absolutely, even, yeah I got out and I think it took me like a week to recover. (*Megan*).

Another participant identified that SUs needed to be made aware that certain activities might be triggering so they could prepare in advance:

> I thought that if anyone did do it in the future, they needed to be aware that it could trigger, that the level of robustivity (if that's a word) needs to be monitored themselves. Be able to like think, "hold on a minute, oo I'm not happy about this" and leave the room. (*Jamie*).

One solution to this might be to offer a debrief period, an opportunity which can be lacking in some involvement activities:

> So it would be nice to have like possibly, not everything needs it, but possibly a sort of erm, on things that possibly could be different like quite intense, you have a facility where you can say, have the confidence to put your hand up and say, ‘[clinical tutors], just 10 minutes at the end.

> This happened. What do you think?' And they either say 'that's really good what you've said. Right, let's get back in the room and discuss it with the trainees', or say, 'right, okay. What we gonna do about this? Because we're not sending you away from this feeling bad about yourself' (*Jamie*).

However, the lack of opportunity for debriefing seemed to be a rare phenomenon, with participants reporting elsewhere that this was available on most programmes.

Contrastingly to most, one participant felt the environment could be more supportive and suggested workshops might be helpful to offer guidance of what is expected:

> I think there's a bit of a gap that people just kind of like, 'oh you've lived the experience, you can just go and talk about it', but actually, yeah you can just go and talk about it but it's really helpful to know, in what context you're talking about it and how that connects with what they're learning and things like that. (*Claire*).

Subtheme 1b: Group dynamics. The shared experience of mental health difficulties and thus the sense of not being alone was something which seemed important to participants, with numerous participants making reference to this:

> But what we do accept I think is an understanding that we've all had problems. And that differs from other groups of people. I mean, because that's not the case. You know, here we know we're safe in that we've all experienced difficulties and there's a connection due to that. (*John*).

Furthermore, a sense of having survived was important; "It is good that we've survived. It's kind of like being alumni from the same hospital. We've all these shared experiences" (*Russell*).

The shared understanding of what it is like to have difficulties also makes usually difficult situations easier:

> I feel that I can say "I have social anxiety, going to lunch, for me, is a nightmare. Do you want to go for lunch?" And then they go "me too". "And if we don't talk, is it a problem?" "Of course not." (*Jamie*).

There was also a suggestion that due to the mutual connection it might be helpful for certain involvement activities to be done together with another SU, suggesting that isolation appears to reduce the sense of safety:

> I certainly think it could be improved if there was more than one of us on selection day, because we would support one another in a different way, because the teaching staff are all busy and getting on to the next thing. (*Kimberley*).

One participant who only engaged in teaching sessions with a clinician and thus was unaware of the other SUI on the program desired more of a connection with others:

> I have no idea what other service user involvement there is, absolutely nothing and I do feel quite remote with that...I think it would be really good to have the option of, you know, like a biannual group or something like that, that people can, just meet with other people and share experiences…because you can learn a lot from other people's experiences. (*Claire*)

This could be interpreted to further suggest that the absence of being connected with and belonging to a SU group leads to isolation which can impact on how safe one feels in their involvement work due to a lack of opportunity to be supported by others in a similar situation.

One participant highlighted that “with an established group when you come along it's overwhelming” (*Sheena*). This can lead to feelings of anxiety; “And when I first started it was quite anxious because, you know, it was an established group working together and you come in”. (*Dawn*).

Other participants described how some SUs might dominate; “Sometimes there are one or two people that either dominate or you can feel a bit, intimidated is too strong a word, but a little bit uncomfortable with” (*Emma*).

There was a sense that less confident group members or those who do not attend as frequently might struggle to contribute; “They didn't come for quite a while and when they came back, they clearly it was very obvious at the meeting, they clearly struggled to feel part of it. To actually feel part of it” (*Kimberley*).

Conversely, new people coming into the group might upset the established dynamics which John described can be difficult for existing members. To overcome these difficulties, participants highlighted that being mindful of giving others opportunities in the group is helpful, for example “I mustn't hog teaching sessions when somebody else is wanting to do that” (*John*). This seems to have already been established in some groups; “…say you've had a go last year, you give someone else a go and so it's like a mutual understanding which is really nice” (*Kimberley*).

There was also a consensus that group members need to welcome new group members; “…when somebody new joins the group we, one of us will be the sort of mentor for them, just the person that will check in with them” (*Emma*).

This might also extend to “making sure that everyone who wants to speak can speak” (*Abigail*), as reflected by another participant; “…sometimes you actually need to try to draw people out or to try to try to actually give them a bit of space to say what maybe what they need to say” (*Kimberley*).

Overall, there was a sense that there was little confrontation or animosity in the group; “So if it was a case of, you know, you're kind of having that sort of confrontation all the time, then yeah, of course it would be different but thankfully it's not like that within the group” (*Craig*). It may be the management of dynamics which prevents confrontation.

It was also highlighted that “a lot of them [new service user representatives] just don't come back” (*Joy*), with another participant reflecting that “one or two people have come in full of ideas for whatever it is. And then, bang they're gone…” (*Kimberley*) leading to questions as to whether this is as a result of the group dynamics not being dealt with or managed well enough by

SUs and staff or whether these SUs found it too difficult or overwhelming to join an established group.

Theme 2: Meeting challenges

The initial challenge relates to becoming involved. Kimberley and Dawn spoke of getting up to speed with practicalities and how things work; “And also learning all the terminology, or the way things are done, the way the university operates, more like being in business. And it was just erm, and oh, the language, and yeah, the shortenings, you know” (*Dawn*).

Another participant reflected on how entitled they felt to sit alongside others who they perceived to have more knowledge; “I sat there terrified. I thought, I don't know why I'm here. This is beyond me. These people are clever. These people talk a language I don't understand” (*Jamie*).

This uncertainty extends into other involvement activities, particularly those whereby participants perceived there to be a lot of responsibility, for example at selection:

> …the most daunting probably thing was was being involved in selection because there was quite a lot of anxiety among service users about our entitlement to actually be involved in choosing you guys [trainees], or being, not choosing you, but actually having some sort of say in in people who were admitted onto the programme. (*Kimberley*)

Participants also described a sense of uncertainty in terms of the expectations of involvement; “…when you first become involved it can seem very interesting, but also quite daunting because there are so many potential avenues that you can go down or potentially become involved with” (*Sheena*).

Another participant reflected that they were initially anxious to put things forward and did not know if what they were sharing was appropriate:

> But like, initially, I was like, "is there a line? Where is the line? I'm not sure where that is. And I'm not sure whether that's my line or other people's line. What do they want to hear? Is that too much for them to know?", that sort of thing. (*Claire*)

It was suggested that the responsibility of being part of selection can be difficult emotionally:

> …it's a little bit stressful in terms of making a decision on you know, if someone's fit to, fit to come on the course and with that there's a lot of responsibility that's involved… it is a pretty long day, you know? And it's, psychologically, it can be pretty demanding, even I would imagine for a normal person to do that…it just wears me out a little psychologically (*Ross*).

However, participants did describe increased confidence over time, suggesting perseverance pays off; “And, you know, as they say feel the fear and do it anyway, and it really has, yeah, really has developed my confidence” (*Dawn*).

Theme 3: Sense of purpose, worth and value

Subtheme 3a - Feeling listened to and valued. There was a sense that SUI is encouraged, and SUs are made to feel included by being invited; “…they ask me. They say ‘would you like to get involved with this or with that?’ And I say yes or no, it's my choice” (*David*)

Feeling valued was also contingent on trainees listening and being receptive to their ideas; “I felt like the trainees were very receptive and understanding as well. And I felt like I really felt like they took it to heart and will take our advice” (*Megan*).

For some participants it was receiving positive feedback from trainees which made them feel valued; “…the feedback was like astounding, actually. And really made me feel really good actually” (*Claire*).

Some participants described changes happening as a result of their contribution, thus demonstrating a sense of control and power. For example; “Like I'm actually feeling listened to, like and that changes are coming about from what I'm saying within those meetings. And actually feeling like something's going to happen with what we've said, like an outcome” (*Abigail*).

As a result, one participant described how despite having initial concerns, involvement does not feel tokenistic; “I was concerned that there may

be an element of tokenism to involvement. But actually, that couldn't be further from the truth" (*Sheena*)

There are however occasions whereby the dominant feeling of being valued is questioned as a result of SUI not being prioritised:

> It made me think, are we actually being valued or are we just a token person? And I hate saying that because that's, there's lots of talk on the programme about services users not being token people. And there are so many examples of where we are not token people…But a few times, just two or three times it's been where a whole teaching session or a half day teaching session and my bit has been left right to the end and then left not with, with about a third of the time that it should have taken. (*John*)

On some programmes SUs were paid equally which increased feelings of value by addressing any power imbalances; "…the thing is we're paid as well, and we're paid the same rate as a psychologist. So that helps you have, feel value as well, you know, that they think you're worth it" (*Dawn*).

Subtheme 3b - A positive way to feed back into the system. An increased sense of purpose by being able to put their difficulties to good use in clinical psychology training was described; "It's made me realise that my past experience and views of mental health problems can be sort of, put to good use". (*Emma*).

The good use that participants described seemed to centre around ultimately helping others who have been in a similar situation; "…well I've gone through this maybe I can help other people not to go rock bottom like I have". (*Megan*).

Participants shared that they were able to offer a new perspective to trainees and potentially make a difference to future services; "…now I think maybe I am more of an expert by experience, I do have expertise in all of these different areas and I'm using them to change like the profession for the good" (*Abigail*).

Another participant shared that making this difference may help a SU:

> …someone may decide not to do something with their life because of their interaction with the trainee from the DClinPsy course, and that person's life may be saved. And that could have just been from a, I may have made a tiny little comment in that trainee's progression, where that trainee's thought 'I've never really thought about it like that, the textbooks don't say that, but I'll bear that in mind in the future' (*Jamie*).

There was a shared altruistic nature amongst participants and using this in their involvement work led to an increased sense of purpose and worth, as summed up by one participant:

> …there's no feeling quite like it if I'm really honest…it just makes you feel so, so good because you know, at the end of the day, you know, I like working with people, that's one of the things that I've done throughout most of my life. And so, it kind of gives that sense back, that sense of purpose and you've really helped someone and that to me is something that's really important, if I can help someone then I feel like twenty times better again. (*Craig*).

As a result of an increased sense of purpose, one participant described, "when I'm doing it [involvement], I'm proud of myself for doing it" (*David*), a sentiment which was also shared with other participants.

For some participants, a sense of purpose was particularly important considering their place in the lifespan, with a sense of purpose confronting potentially ageist views whereby society might perceive that older people do not have much to contribute; "And it's sort of even in later life, it's kind of made me feel as if I've got a use, I'm useful, erm I've got a purpose". (*Dawn*).

Involvement also helps give a sense of social status; "So peers of mine that may be my age are very impressed by the fact that I'm actually still doing this, that they perceive as a kind of, a similar job to what I did, but volunteering it". (*Joy*).

Theme 4: The person you see now is not the person I was

Subtheme 4a: A game changer for personal growth and development. Personal growth was an important way in which SUs indicated

they had changed since involvement. For example, becoming a “much more positive person” (*Emma*) was an unanticipated consequence of involvement; “It's a bizarre side effect of the reason I come, which is for the trainees and everything but I'm, I'm gone ‘oh my God. Oh my god. The side-effect is I'm a better person. Who'd have thought that?’ ” (*Jamie*).

The same participant described how those closest to them had also seen a transformation due to being involved; “I wanted her [girlfriend] to be part of your research because I wanted her to come in and give an observer's viewpoint about how attending this group alone has transformed me as a person”. (*Jamie*).

Feeling valued alongside improved communication and therefore improved relationships also had a positive impact on sense of self and quality of life:

> My sense of self had really disappeared and I felt very worthless. And so my sense of who I am and my function day to day has certainly improved. And I know that some of that is obviously going to be partly down to continuing therapy. But I would say it's also a part of my life that I really enjoy and I know has benefited me in general in terms of, you know my life and my relationships with other people and my sense of being able to communicate and feel a valued member of society, which I certainly didn't before. (*Sheena*)

It was indicated that improved social functioning as a result of involvement also led to reengagement with an important aspect of identity:

> …so at the point where this [involvement] was suggested I was barely speaking to a human being or let alone leaving the house…because I think it's fed into a natural instinct to almost, despite whatever condition physical or mental I was in, to try and help other people... And so yes it has been very, it has very much affected how I feel about myself and the quality of life that I now have. (*Sheena*)

For others, increased social engagement that involvement brings meant they felt less isolated; “I guess it kind of makes me feel better in a sense that I'm kind of less isolated…” (*Craig*).

However, this was contingent on involvement, as without involvement isolation can reoccur which also impacts on mood:

> And then when I'm not [involved], sort of like, like I said before you can kind of come into that isolation if you like and then that can sort of make you feel like, well, yeah, then you can start to feel low about it. (*Craig*)

Self-confidence was another aspect of personal growth; “[Before involvement] I think, I would kind of do myself down a bit. Not give myself credit for what I can do”. (*Dawn*).

Another participant described how she felt more professional as a result of involvement and that this actually impacted on her husband’s care as she was “treated more respectfully”. (*Joy*).

Participants described how involvement has helped them grow personally and has also helped alleviate difficult feelings:

> I'm developing as a person mentally, physically and socially and everything, all because of [involvement]. It's, it's been a a massive game changer. And I've suffered a lot from loneliness as well and knowing that, in a couple of weeks’ time, I've got that in my diary, and it may be only an hour, but I can go to somewhere where I'm respected and I feel valued and I value myself, that's the key thing. (*Jamie*)

Involvement has also helped give direction to one’s life:

> I didn't really know where I wanted to go in life. I knew I wanted to do something with mental health, but I didn't know what it was and I was like, actually, I have these skills that I'm not using and I can use them in this way. So it was like a massive wake up for like, oh, this is what, this is what I can do. (*Claire*)

The same participant went on to describe how this led to further opportunities and how her professional identity has been particularly important to her when other aspects of her life have been difficult:

> Like I started off volunteering a little bit and just doing this stuff [involvement] and then from the stuff, from that I did a research poster and that went to a conference and it won a prize and people started recognising me and asking me my genuine opinion on things or to contribute to things and it just sort of like, that's been a huge thing in my life that's carried on moving forward, where everything else might not necessarily be moving anywhere or moving backwards even, that's always carried on moving forwards. (*Claire*)

Some of the other involvement activities described included interviewing at a local mental health trust; “I do interviews for the local mental health trust now…But I wouldn't have had the confidence to do that without being part of [involvement]”. (*Emma*).

Subtheme 4b: Relating to difficulties in a different way. Participants described how having access to theoretical information was more insightful than being “rubberstamped” (*Jamie*) with diagnoses which were “never explained” (*John*) in services.

In particular, attachment theory was found to be insightful:

> And one of the main things I learned, which I'm amazed that I'd never been told about it before, especially by my therapist, was attachment theory. And I found that attachment theory explained my life to me, explained why I'd had mental health problems. *(John).*

Kimberley also shared this view, stating she had “spent whole days, for example, learning about attachment theory and so on. And that was absolutely revelatory, really, for someone who had never had any psychology training”.

By having this increased understanding, one participant described how they were kinder to their self; “Because I understand a bit more I guess I'm a bit kinder to myself as well because I know the process and what it means so, yeah it doesn't feel alien to me anymore”. (*Megan*).

It was also suggested that involvement helps overcome stigmatised views of mental health placed upon individuals by society:

> …it's [involvement] helped improve my own feeling of self-worth, because after becoming very ill, you know, mentally, my sense of self-worth went through the floor. And you just feel like a burden on society and good for nothing. So really all this service user involvement has been so good. (*Dawn*)

Reducing stigma was important to several participants. One participant described how relating to their difficulties in a different way had given them confidence to speak about their difficulties in the outside world where stigma can often exist around mental health difficulties:

> I've said, I have a mental health condition. And I've not been talking about this. In fact, I've been terrified of talking about it. And now I'm talking about it...I've had the confidence to say this is who I am. This is in the outside world. Not just here… I'm different. Let's celebrate it for a change. And in the outside world it's been very difficult for me to celebrate that…I can be a fantastic contribution to society and still have a mental health condition. And I couldn't have done any of that without [involvement]. (*Jamie*)

Subsequently, being involved can lead to feeling less persecuted:

> I can look back and sort of one person and be talking about it from like, like I'm a different person in sort of subtle ways in sort of not feeling so, I don't know, despondent or persecuted or, a much more positive person. (*Emma*)

One participant described that being able to engage in involvement meant she was better able to live alongside her difficulties:

> I just had this little afternoon feeling like a normal person as opposed to a mental health person. And that was really important. And although it didn't solve all the rest of my problems it was just a little chink of "I'm still here. I'm still here behind all this chaos that's going on". (*Claire*)

Subtheme 4c: Reengaging with skills that I thought had gone.

Increased confidence arose as a result with re-engaging with a skill they thought they had lost:

> …it (teaching) was a real loss when I lost it. So kind of sort of being asked to sort of stand up again… And then and then when it kind of starts coming back, you feel that that was a real plus. It was a real, it gave me something that that I thought was gone. (*Kimberley*)

For three participants, involvement came about post-retirement and whilst it enabled reengagement with an aspect of their identity they had lost, for one participant it also prevented potential low mood:

> And it provides me with intellectual stimulus. I was worried when I thought about retiring from teaching because I would get depressed in the holidays because there wasn't the stimulus. And I was afraid when I retired…that that would be something that I would lack. And it's given me that intellectual stimulus. (*John*)

Dawn could also relate to re-gaining intellectual stimulus, stating that involvement has “woke my brain up” and “keeps you sharp”.

For another participant, involvement was a different way to tap into their altruistic nature after they were no longer able to help in other ways:

> And at the time I was quite gutted because I was like a regular blood donor and due to complications at my daughter’s birth I had to have a plaque transfusion so which meant I couldn't do it anymore. And I was looking for something to help basically.. (*Megan*).

Theme 5: Wanting to break the glass ceiling

Although participants did not give specific examples of how they have tried to break down these barriers, there did seem to be a desire to do so:

> I think there is a glass ceiling. I think there is one…there are also certain parts of the programme which I know I've requested to be involved in and it hasn't been, it hasn't happened. I haven't precisely been turned down, but it hasn't happened. And there are things that I feel I could, I wouldn't,

> I wouldn't ask if I didn't feel I had something to contribute. So I think there are, there are areas where we have some control and there are areas where we don't. (*Kimberley*)

Jamie described how although SUs get to decide on what they are involved in, budgets can be a barrier to how much they would like to be involved; “But we have a very strict budget and sometimes [the involvement group] just have to say, ‘we'd love to, but we just we can't afford it’ ”(*Jamie*).

The issue around budgeting raises questions about whether SUs truly have decision-making power if budgetary constraints are imposed by others. However, it might be argued that any employee is constrained by budgets imposed upon them and therefore this might imply that SUs are actually treated more like staff.

Finally, there was a recognition that a lack of knowledge in a particular area can mean that certain topics may never be SU led; “Sometimes a topic may come up that means that it cannot be service user led… something like maybe statistics, you know maybe not everybody has had experience of working with statistics” (*Sheena*).

Overall, there was a sense that whilst SUs might feel included and they maximise the opportunities presented to them, there are limits to their involvement:

> So, whilst knowing that I'm I'm not obviously as full a part of the programme as [trainees] are, or, the tutors are, I'm not made to feel lesser in a way. So I know I'm not a full part, but I feel that as much as I can be part of this group, I am part of this group. (*John*)

It was unclear what participants meant by ‘full’ involvement, but considering this in the context of the Ladder of Involvement (Tew et al., 2004) it would suggest that involvement in clinical psychology training does not equate to partnership, possibly as a result of issues around power.

Discussion

The following section offers further discussion of the results alongside the evidence base and psychological theory. This section will also discuss the relevance of the research to clinical psychology and an evaluation of the research including implications, strengths and limitations. Finally, some of the researcher's critical reflections experienced throughout the research process will be outlined.

The research aimed to explore SUs'/carers' experiences of the personal effects of involvement in clinical psychology training. The research is one of the first to explore the personal effects of SUI in clinical psychology training and to the researcher's knowledge is the first to do this across multiple training programmes.

Analysis revealed valuable insights into the personal effects of involvement including the environment determining a sense of safety, meeting challenges, a sense of purpose, worth and value, shifts in identity and wanting to break the glass ceiling of involvement, all of which can help inform future involvement in clinical psychology training, including how to optimise involvement for SUs/carers.

The results also go some way to assisting SUs/carers who are considering involvement in clinical psychology training to make an informed choice about whether and how to become involved in light of the findings which outline other people's experiences of the personal impact.

To deepen the understanding of the processes which might underpin the experiences of involved SUs, elements of each theme will be considered in more detail below alongside psychological theory.

Determining a sense of safety

It was identified that supportive relationships with staff are particularly important at times when the environment might be triggering for SUs. As the previous involvement in clinical psychology training literature has focused mainly on implications for trainees (Harper et al*.,* 2003; Schreur, Lea & Goodbody, 2015; Tickle & Davison, 2008), the finding that the environment has

the potential to be triggering is unique to the current research and is important for two reasons. Firstly, although participants desired to be treated as colleagues and were keen to point out they were not there for psychological support, clinical course staff have a responsibility to support service users if they are triggered by topics within involvement and there were examples whereby this support had not always been given. Although it has previously been argued that staff need training in how to offer support to SU representatives (Repper & Breeze, 2007), it is suggested that as the majority of staff on clinical psychology training programmes are qualified clinical psychologists, they should be able to use their clinical expertise to minimise the impact that discussion of certain topics might have on SUs where possible (e.g. through joint planning of sessions and by offering debriefs), whilst also being able to offer support to SUs when the environment is triggering. Secondly, this finding is important because it allows individuals considering SUI in clinical psychology training to make an informed choice in the knowledge that the nature of the training has the potential to be triggering. Rather than being a decision of whether to be involved or not, those considering involvement (or SUs who are involved) might want to choose involvement activities that are less likely to cause distress as this is likely to be unique to each individual in terms of their mental health difficulties, triggers and point in recovery.

Participants' sense of safety also extended to practical support offered by staff members, with a particular focus on being provided with food and drink. It might be said that as food and water are one of the core physiological needs of Maslow's hierarchy (Maslow, 1943) meeting this basic need allows involved SUs to move up the pyramid through safety and security, belonging, self-esteem and towards self-actualisation, many of which are represented in the themes identified.

The sense of mutual survivorship that individuals felt within their SU group was also important in determining participants' sense of safety and might be better understood by considering Yalom's processes of group development (Yalom & Leszcz, 2005) as well as social identity theory (Tajfel & Turner, 1979). Being part of the involved SU group gave participants a sense of not being alone with their problems and a sense of belonging and connection (fitting in

with Yalom's ideas of universality and group cohesion). Considering social identity theory, these factors led to involved SUs feeling part of the 'in group'. As participants also reported that involvement helped to reduce isolation and societal stigma around their mental health difficulties, being part of an 'in group' is likely to be particularly important if those same SUs have been part of the 'out group' in society. Indeed, connectedness is an important part of the personal recovery journey in mental health (Leamy et al., 2011). Therefore, although perhaps not the primary aim of involvement in clinical psychology training, involvement which builds a sense of connection and belonging to a group of similar people is likely to be beneficial for SUs who may have struggled to experience this in other aspects of their lives, thus helping them to overcome stigma which also ties in the with CHIME framework (Leamy et al., 2011).

Whilst identity can be influenced by changes in group identification (Tse et al., 2012) findings also revealed the potential for there to be difficulties identifying with the SU group due to being at different stages of recovery. This is perhaps something SUs who are considering involvement should be aware of and suggests that in involvement a seamless transition to being part of the 'in group' might not be as easy as social identity theory proclaims. This finding also seems to challenge the idea that similarities with the 'in group' are exaggerated to enhance identity (Tajfel & Turner, 1979) within involvement, as some participants readily explained how there were differences within the SU group.

Difficult group dynamics was an aspect which participants identified could threaten their sense of safety. Initial anxieties about joining an established group were reported and this might be understood in terms of going through a process of re-orientating to a new group, something which has been found to be a stressful process in the involvement literature (Iyer, Jetten & Tsivrikos, 2008). Participants also highlighted a power imbalance between new and existing members, potentially indicating that expert power (French & Raven, 1959) was at play within the SU group. Useful attempts to overcome this might be mentorship of new members or encouraging contributions from them. It might be argued that going through these initial difficult stages of group development enables the development of socialising techniques (Yalom & Leszcz, 2005) and this might also explain some of the findings in theme four whereby participants

described improved social functioning as a result of involvement. Prospective SU members might be encouraged by this finding which suggests that although initial group dynamics can lead to feeling unsafe, if these are managed by the SU themselves in conjunction with other group members it can actually be of great personal benefit longer term.

Challenges to involvement

Challenges to involvement were identified that had the potential to cause distress. Many of these challenges centred around the concept of power and entitlement. For example, participants spoke of the initial difficulties working alongside professionals who they perceived to hold more knowledge and more power, thereby suggesting course staff are perceived to have 'expert power' (French & Raven, 1959), particularly in activities where there is more responsibility such as at selection. Despite the challenges, participants described realising over time that high levels of education do not equate to more knowledge, with this realisation enabling SUs to take on the 'expert' role. This led to participants describing an increase in confidence and empowerment, which in turn likely positively impacted on their sense of identity. This finding is important for professionals who work alongside involved SUs in clinical psychology training, as the perceived power imbalance may impact on how comfortable SUs feel at challenging their opinions which could have implications in activities such as selection whereby SUs should have a different perspective to offer. It might be useful to explicitly highlight and hold discussions around the idea of expert power when SUs first become involved, a skill which the Division of Clinical Psychology (DCP, 2010) suggests clinical psychologists are apt at.

SUs and professionals should also be aware of the emotional impact that involvement can have including feeling uncertain, scared, anxious and drained. Accessing support at these times might be contingent on SU representatives feeling in a position of safety as discussed previously. This further solidifies the importance of time and effort being put into the building of relationships between professionals and involved SUs, so that SUs feel safe enough to seek support at these times.

Sense of purpose, worth and value

Feeling listened to in involvement was important in determining how valued participants felt. Staff listening and the implementation of SU ideas were particularly important in determining value. Thus, SUs felt more valued when their ideas were implemented suggesting they had decision-making power (Lukes, 1974), in contrast to when decisions were already made by professionals (exerting non decision-making power) (Bachrach & Baratz, 1972) or when professionals exerted their expert power (French & Raven, 1959). This could have implications for SUs who are still in recovery from their difficulties considering empowerment is one of the typical characteristics of the personal recovery journey in mental health (Leamy et al., 2011).

To increase the chances of SUs feeling valued, reflection by professionals and wider stakeholders (BPS, HCPC, employing Trusts) is encouraged to actively consider the value of SUs who contribute to training and how they might demonstrate this. It is also important to reflect on how to manage expectations, for example by sharing a rationale if some decisions cannot be shared with SUs.

A fundamental finding that those seeking to involve others in educational settings should recognise is the identified relationship between being paid equally and an individual's subsequent sense of value. This is a replication of the finding by Campbell and Wilson (2017) who also linked renumeration with value in clinical psychology training, however the present research goes further by finding that different courses take different approaches to payment (with some involvement paid fully, some partially, some voluntary). As well as helping to address power issues (discussed in journal paper), the provision of equal pay is also important bearing in mind the finding in the present research that being treated as equal members of staff was found to be a predeterminate to SUs sense of safety in involvement. The disparity between whether and how participants were paid was surprising considering research back in 2007 highlighted that systems of payment needed to be put in place for involvement in healthcare education (Repper & Breeze, 2007), hence the recommendation for a more standardised system whereby those involved are paid equally across clinical psychology training courses. Those developing such a system should

take into consideration guidance such as the reward and recognition document (Department of Health, 2006) which outlines in more detail recommendations regarding paying SUs for their involvement. Some of the challenges to offering payment should also be considered, for example the implications that payment might have on those SUs claiming benefits and therefore the provision of payment should be fully discussed with SUs.

SU representatives described feeling a sense of purpose and worth by being able to put their difficulties to good use. Whilst this clearly links with altruism in Yalom's theory of group development (Yalom & Leszcz, 2005), the theory does not necessarily explain the process underpinning why altruism can lead to a sense of purpose and use. In involvement, this process might be explained by considering the bases of social power (French & Raven, 1959). It may be that by being able to exert expert power (e.g. trainees looking to SUs to bring in their expertise) and informational power (Raven, 1965) (e.g. being in a position to share information), SUs feel a sense of empowerment enabling them to act in an altruistic way. Both of these concepts then likely combine to leave SUs feeling an increased sense of purpose and worth which also helps facilitate a more positive identity than one they may have held in the past when they have been on the receiving end of help and not felt empowered within services whereby the balance of power is not equal (Felton & Stickley, 2004).

Overcoming stigma is also a key part of developing a positive identity (Leamy et al., 2011) and this might go some way to explaining the finding that involvement was particularly important for those later in the lifespan or for those whereby other aspects of their life were not going so well. Therefore, considering that a sense of purpose has been linked with positive psychological consequences (Haslam et al., 2009) and can also develop a positive identity, it is important that involved SUs feel empowered enough to be able to draw on and use their difficulties in a way that is meaningful to them and to trainees.

The person you see now is not the person I was

Participants described personal growth as a result of involvement. Increased confidence had led to pursuing of other opportunities outside of involvement and an increase in meaning and quality of life, implying hope and

optimism about the future, important parts of the personal recovery journey in the CHIME framework (Leamy et al., 2011). This suggests that involvement has the potential to help SUs facilitate or continue their personal recovery, a benefit of involvement which SUs considering involvement might wish to be aware of.

Overcoming stigma was important to enhancing participants' identities. This makes sense considering overcoming stigma is a key part of building identity in the CHIME framework (Leamy et al., 2011). Although the primary aim of involvement in clinical psychology training has been described as helping to deliver the curriculum (BPS, 2019), this finding suggests that involvement can actually make a meaningful difference to SUs perception of themselves and thus it might be argued that involvement could also serve as a continuation of a SU's recovery. Therefore, SUs might wish to explore other avenues for involvement which might be beneficial to them, including via mental health trust involvement initiatives or community groups. This type of involvement has also been linked with personal recovery (Walsh & Tickle, 2017).

A unique finding to the current research is that involvement in clinical psychology training gives participants opportunity to reengage with skills they thought they had lost. As well as rebuilding identity, reengagement with skills also ties in with common aspects of personal recovery – namely re-engagement with life and restoration of sense of self (O'Connor & Delaney, 2007). Involvement whereby SUs can reengage with skills therefore has the opportunity to enhance personal recovery for SUs. However, it should be highlighted that participants who used to teach are over-represented in this theme and although there are other skills that SUs might re-engage with, those who do not possess historical teaching skills and experience may not gain the same opportunity to reengage with skills.

Wanting to break the glass ceiling

In line with previous research suggesting the amount of involvement in mental health education can vary widely (Happell et al., 2014), participants described different levels of involvement dependent on the programme they were involved with. Whilst this theme suggests SUs are not involved to the extent that they might wish to be in clinical psychology training, this may not

solely be due to power imbalances between course staff and SUs. It might be suggested that as clinical psychology training programmes have to follow set curriculum standards from the HCPC and BPS and ensure trainees meet proficiencies in a limited time frame, some SU requests that do not meet with this may have to be turned down. This raises further questions as to how much SUs are involved in developing the accreditation criteria, curriculum and proficiencies for training of clinical psychologists, as they should be if collaboration or partnership involvement is to be achieved (Tew et al., 2004). Although this is beyond the scope of the present study, future research may wish to explore the extent to which SUs are involved in developing the HCPC/BPS standards for training clinical psychologists, as it is likely that the legitimate power (French & Raven, 1959) of the organising bodies impact on the amount to which SUs can be involved in the direct delivery of training on individual programmes.

Furthermore, when aiming to empower SUs in clinical psychology training, there may be degrees and stages of power sharing which need to be taken into account. For example, SUs adjustments to the role, reconciliation of multiple identities and acknowledging their own expertise may mean that handing over power needs to be a gradual process with complex negotiations between programmes and SUs.

Theoretical implications

The theories identified in the introduction will be briefly discussed in relation to the constructed themes in this study.

Considering social identity theory (Tajfel & Turner, 1979), participants described how a sense of group survivorship and shared experience helped facilitate a group identity amongst involved SUs. However, whilst the theory proclaims that differences between ‘out groups’ are often exaggerated to enhance a group’s identity, this did not seem to be the case for involved SUs. In actuality, some participants explained how there are differences within their own SU group in terms of being at different stages of recovery. This might suggest that having the title of SU representative is not enough for participants to feel part of the ‘in group’, and it should not therefore automatically be assumed that

SUs will feel part of the group due to having varying experiences and likely multiple identities. This perhaps adds strength to the notion that SU representatives should be treated as humans first (Lea et al., 2019) as opposed to being seen as a homogeneous group within clinical psychology training.

Lukes' (1974) dimensions of power could be applied to participants' experiences, namely the concepts of decision-making power and non decision-making power. Findings suggest that involved SUs felt more valued when they were able to exert decision-making power, but in actuality there were examples whereby professionals exerted their non decision-making power by controlling the agenda to limit decision making or already making decisions prior to consulting with SUs. Applying his theory has been useful in discovering that in clinical psychology training the power still appears to lie with the professionals as opposed to the SUs and that power seems to largely come into play when there are decisions to be made either about the level of involvement or course content. The concept of ideological power was not implied in the findings of the present study, perhaps suggesting that the ideology in clinical psychology training is not pervasive to SUs, meaning there is room to grow their involvement further within the supportive environment that participants described.

Similarly, aspects of French and Raven's (1959) five bases of social power were evident in participants' experiences. Perhaps the most referred to social power was expert power. This makes sense in that by nature of their profession it would be expected that professionals on course programmes would have special knowledge or expertise, whilst it might also be said that SUs also possess special knowledge or expertise having used services. It would appear that initially involved SUs find exerting their own expert power difficult and even question this in relation to professional's expertise and those of fellow SUs. Whilst the present study uses expert power to explain some of the findings, the concept of legitimate power might also be applied. It became apparent that there might actually be overlap between a person being powerful due to their elected position (legitimate power) and them having special knowledge and expertise (expert power), suggesting that it might be too simplistic to separate power into five distinct categories.

Applying the concept of informational power (Raven, 1965) to the findings was helpful in finding that, by nature of being involved in a clinical psychology training programme, theoretical information is not withheld, whereas in services information is not shared as openly. Involved SUs therefore have the potential to greater understand their difficulties. Applying this aspect of the theory has been useful in discovering that professionals exerting informational power might be a contributing factor as to why there are historical profound inequalities of power between SUs and mental health professionals (Felton & Stickley, 2004). Withholding information also seems to limit recovery, given that participants found alternative and useful explanations of their difficulties, which promoted recovery, through learning about psychological theories they had not been exposed to in services.

Another theory which was considered alongside the findings was Yalom's processes of group development (Yalom & Leszcz, 2005). Ideas of universality and group cohesion tie in with participants' experiences of a sense of belonging and connection within the SU group, although as discussed above this was not always the case. Yalom's ideas of altruism and developing socialising techniques were also evident in the findings. Therefore, although not a therapeutic group, the findings reveal that being part of a SU group still has potential to bring about positive change for individuals within the group. Professionals and SUs should be aware of this and might look to help SU groups build upon aspects of Yalom's theory to increase the chances of SUs gaining personal benefits from involvement alongside the aim of enhancing trainees' education experience.

Finally, the findings were looked at through the lens of the CHIME framework (Leamy et al., 2011) to consider whether involvement might help enhance personal recovery. All aspects of the CHIME framework were evident within the findings as a direct result of involvement activity – namely connectedness; hope and optimism about the future; identity; meaning in life, and empowerment. Although it is acknowledged that personal recovery is a subjective experience (Bellack & Drapalski, 2012) and the views of those no longer involved were not captured, findings being in line with a conceptual framework based on empirical evidence relating to personal recovery suggests

involvement has the potential to enhance involved SUs' personal recovery. Therefore, developing opportunities in which people can experience connectedness, hope and optimism about the future, meaning in life and empowerment are important, whether in education and training activities or elsewhere.

Relevance to clinical psychology

The research has offered insights into the personal effects of involvement in clinical psychology training for SUs. The findings offer insight into areas which can be improved to optimise the experience for involved SUs. By optimising their experience (e.g. fostering safety), it is more likely that they will be better able to engage in involvement activities. This is important for SUs considering the potential personal benefits described above. Optimising involvement is also important to clinical psychology and future clinical psychologists due to the benefits that SUs bring to training programmes (Blackhall et al., 2012; Clarke & Holttum, 2013; Harper et al., 2003; McCusker et al., 2012; Repper & Breeze, 2007) and thus potential benefits to SUs whom clinical psychologists go on to work with.

Although not the original research aim, the research has also highlighted a potential improvement in clinical psychology practice. Sharing of theoretical knowledge appeared particularly important so that SUs could better understand their difficulties and the research highlighted that this does not always happen in services. A theory which was specifically mentioned was attachment theory and it may be that SUs found this helpful because it removed blame and stigma. If professionals aim to increase the theoretical knowledge that they share with SUs as a result of this finding, the research has the potential to start to change the way services operate so that SUs gain most benefit. Whilst this might be similar to the concept of recovery colleges which use an educational paradigm to promote recovery, it may be that concepts of the recovery college approach (e.g. sharing theoretical explanations) can be better incorporated into clinical psychology practice.

Evaluation of research

To evaluate the quality of the research, the CASP checklist (CASP, 2018) was completed. All ten criteria were met and evidenced (Appendix I) suggesting the research met the quality standards set by CASP for qualitative research.

Implications

When considering the following implications, it should be borne in mind that the research does not represent every involved SU's experience and therefore the results should not be generalised as such. However, as the sample was derived from multiple courses, there are implications for clinical psychology training programmes and clinicians to consider.

Firstly, programmes should aim to create a sense of safety for involved SUs. Similar to in organisations (Carmeli, Brueller & Dutton, 2009), high quality relationships and connections were vitally important in creating the sense of safety. Therefore, to optimise the involvement SUs and programmes might want to specifically focus on the relational factors which have been associated with psychological safety in the literature, including carrying capacity, tensility, connectivity, mutuality and positive regard (see Carmeli *et al.,* 2009). Further research considering SU perspectives might help to determine how to optimise these aspects of high-quality relationships between SUs, staff and trainees, who all hold distinct roles in clinical psychology training.

Those considering involvement should be aware of the findings of this research to support them to make informed choices about whether and how to be involved. New involved SUs should be aware of potential difficulties when joining a new group including power imbalances and being at different stages of recovery to other SUs. This experience should be normalised by staff and SUs on the programme to try to promote continuing attendance as it has been found that being able to overcome these initial barriers can actually be beneficial for SUs (Yalom & Leszcz, 2005).

Professionals on clinical psychology training programmes should be aware of power imbalances that involved SUs can feel in relation to their expertise versus that of staff. Clinical psychologists on the programme should

use their professional skills in handling power imbalances to address the power imbalance and empower SUs to use their expert power (French & Raven, 1959). This might include explicitly highlighting the imbalances of power and inviting SUs to reflect on this and jointly develop solutions, within the absolute limitations of the programme.

Professionals should also be aware that SUs feel less valued when decisions are already made and therefore involvement seems tokenistic. Efforts should be made to ensure SUs are involved in all decision-making processes, including deciding what the decision is that is to be made. This might include involving SUs in module design as well as being involved in designing the guidelines for programmes at higher levels (e.g. BPS, HCPC).

Those who commission clinical psychology training should be aware that equivalent budgets to staff should be made available to pay SUs for their involvement. The research showed that this is not always the case and that when equal pay is not received this can impact on a person's sense of empowerment, identity and ultimately personal recovery.

Some of the main benefits to involvement identified included a positive change in the SU's perception of themselves, including re-engaging with lost skills. Additionally, the research indicates that involvement could serve as a continuation of a SU's recovery. Further involvement may therefore be beneficial in SUs' recovery journey.

Finally, professionals in mental health services should look to share theoretical knowledge with SUs. Involved SUs found that having access to this information was enlightening in better understanding their difficulties. Efforts should therefore be made to share this information which might also help reduce the profound inequalities of power between SUs and mental health professionals (Felton & Stickley, 2004).

Professionals in clinical psychology training should also be aware of the benefits of sharing theoretical knowledge. They might use the findings to imply that teaching theoretical explanations has the potential to positively impact on a person's wellbeing by increasing their levels of understanding. It would also be

useful to make this explicit to trainees who they teach as they will make up future services and thus may look to adopt this approach with their clients.

Strengths and limitations

Using a TA guided by the principles of Braun and Clarke (2006) ensured an in-depth exploration of participants' experiences which is a strength of the study. Furthermore, attempts were made to capture each participants' experience by analysing each interview transcript in detail. Both of these factors mean the present research has had a rigorous method of data analysis.

A further strength of the research is that it moves beyond previous studies in the area which have recruited from singular course programmes by recruiting from across course programmes, therefore the findings are not representative of how one particular programme operates but more reflective of SU experience of involvement in clinical psychology training as a whole. The findings have also highlighted some differences in how programmes operate (e.g. with regards to payment) which were not possible to highlight in previous studies due to recruiting from one course programme.

However, as the research did not recruit every SU representative or recruit from every programme it is likely that other perspectives might be held by those who did not consent to take part in the research. Therefore, the findings should not be interpreted as representative of every SU/carer involved in clinical psychology training on every programme.

The research aimed to recruit SU and carer representatives, however only two participants identified as carers (and they were also SUs in their own right). Therefore, the personal effects of involvement of carers is under-represented in the current research and future research may wish to specifically explore the experience of carers.

Whilst the research made efforts to recruit SU/carer representatives who were previously but no longer involved in clinical psychology training, no such participants were recruited. Therefore, the research findings reflect the experiences of those who have maintained involvement in training and it is possible that those who are no longer involved may have had a more negative personal experience of involvement, with those people's views not being

captured. It may be that some of the difficulties identified in the ‘meeting challenges’ themes were too difficult for those no longer involved to overcome, or it may be that the environment did not foster a sense of safety. It may also mean that the concept of involvement enhancing recovery is not relevant to every involved SU. However, this would warrant further exploration in future research.

Whilst a cross-sectional design was useful in obtaining experiences of participants at a moment in time, future research might wish to adopt a longitudinal design. This would enable SUs to be followed from when they become involved and throughout their involvement. This might offer insights into how participants experience the personal effects of involvement as time progresses, and whether and how their experiences influence whether they continue their involvement.

Demographic information obtained showed that amongst participants there was a skew towards retirement age, with half of participants aged 60 or above. As a result, cohort effects and likely change in service culture may have all had an impact on participants’ experiences of the personal effects of involvement and this should be borne in mind when interpreting the findings. Future research may wish to explore whether this skew is representative of the involvement population in general and if so why this may be. Future research may also wish to explicitly explore the experiences of the personal effects of involvement for those aged 18 to 40 who are under-represented in this research.

The researcher was a trainee clinical psychologist on one of the programmes where participants were recruited from. The four participants from this programme therefore already held an existing relationship with the researcher. This might have impacted on how open they were with their responses as they would have been aware that the researcher would have further interactions with them throughout their training. The researcher also had some prior knowledge of these SUs’ experiences as a result of hearing about them throughout training to date. Although the researcher made efforts to ensure power dynamics did not impact on the interview process, there may

have been a shift in power whereby in training the SU representatives hold the "expert power" in the subject they are helping to teach, whereby in the research it may have been perceived that the researcher held the "expert power" by way of designing the project and asking set questions to participants. It is also possible that considering social identity theory the four participants affiliated to the same programme as the researcher may have perceived the researcher to be part of the "in group" in relation to being from the same course programme, or conversely may have perceived the researcher as being part of the "out group" because of their role as a trainee rather than a service user. It is not clear whether these factors impacted on the information gathered, but the different and multiple relationship with these four participants compared to the other ten should be considered when interpreting the findings.

As the interviews progressed it is possible that richer data was gathered due to the interviewer's technique improving. Furthermore, it is acknowledged that the semi-structured interview schedule will have impacted on the themes developed. However, the semi-structured nature of the interview did allow the researcher to be flexible which allowed participants to expand on their experiences and guarded against themes mapping directly onto the questions.

Although TA was an appropriate approach to meet the research aims, nuances to participants' speech were not captured in the present research. Whilst the quotations represent the generated themes, it is possible that some quotations might be misinterpreted without the nuance of speech.

The position of the researcher should be considered when interpreting the findings. The researcher is not a SU representative and whilst efforts were made to engage in supervision with a SU representative throughout the research process, this supervision was limited due to availability and time constraints. Therefore, whilst the findings are important in informing future involvement, it may be that the suggested implications would not be the priority of the SUs themselves. The research should therefore not be considered as "giving voice" to the SUs as ultimately the research was conducted and written by a professional which may mean certain aspects of the research were privileged over others.

Unlike in SU-led research (e.g. Lea et al., 2019), the current researcher was acting in a professional capacity (a trainee clinical psychologist) and is not a SU, which might invoke criticisms of the researcher exerting expert power to understand SUs experiences. However, it is argued that it is important for psychologists to make use of their expert power to develop understanding which could ultimately enhance involvement and power sharing. Additionally, as the research aimed to help people who are contemplating involvement make a more informed choice, the research serves as a vehicle to share theoretical knowledge (and therefore power) with SUs to empower them to make the right choices for them.

Conclusion

To conclude, the research has been the first to examine the experiences of involved SUs across multiple clinical psychology training programmes. Whilst some themes are similar to those developed in previous studies, considering experiences alongside psychological theory has helped expand our understanding of the personal effects of involvement. It is clear that involved SUs derive many benefits including developing a positive sense of identity, alongside some feelings of empowerment, worth and value and much of what participants described is in line with ideas of personal recovery, suggesting involvement might be a useful way for SUs to continue their recovery. However, these benefits seemed contingent on the environment fostering psychological safety, via positive and supportive relationships with trainees and staff and SUs being treated as equal colleagues and financially reimbursed as such. However, there are also challenges to involvement and it would appear that there is still some way to go to move towards involvement whereby participants feel fully empowered and involved at nearer to a partnership level.

Critical reflection

Throughout the research I was involved in a process of critical reflection. I kept a reflective diary which aided with this and extracts of the diary will be presented below.

Using a qualitative approach

Since starting training my views on whether there is an absolute 'truth' have changed. Prior to training I feel I held a more positivist stance, however I now believe that a critical realist stance is more in line with my personal views. My beliefs have shifted in a sense that instead of believing we need to try to find a 'reality', we can learn more by exploring one's perceptions of the reality. I believe that this influenced the approach I took to the research.

When deciding which qualitative approach to use, I kept in mind the research aim and my philosophical position. Initially, I found it difficult to distinguish the differences in approaches, particularly between TA and IPA. However, reading Braun and Clarke (2013) and discussions in supervision were really helpful in making the comparisons clearer. Reflecting on my qualitative teaching during training also helped, as well as discussions with my peers who were using different qualitative approaches.

TA seemed a suitable approach due to its flexibility. However, at times I found the flexibility and lack of prescriptiveness anxiety provoking as I was new to qualitative research and wanted to make sure I was 'doing it right'. I therefore opted to be guided by the principles of Braun and Clarke (2006). In hindsight I still feel that this approach was appropriate.

Determining sample size

I found myself getting caught up on how many participants were 'enough':

> *Should I go for 5, 10, 15 participants? It feels like I'm plucking a number out of the air and I wish there was clearer guidance!*

To help me decide on a suitable sample size, I considered the research aims, academic requirements and empirical evidence. On reflection, I feel that my concern with sample size derives from having previously conducted

predominantly quantitative research whereby a larger sample size is needed to ensure the study is adequately powered, and sample size calculations are available. I feel this links to a wider point whereby quantitative studies have traditionally dominated the empirical evidence base in psychology. It felt unusual to me to only be aiming to recruit 10 - 15 participants, but discussions in supervision and reviewing the literature helped reassure me that this sample size was adequate to meet the aims of the study. Considering my critical realist stance also helped as I reminded myself that I was not looking for a 'reality', but rather people's perceptions of the reality and therefore sample size was not as important. With this stance in mind, I reminded myself that the research did not aim to represent everybody's experience.

In relation to sample size, from engaging in the qualitative research process I feel I have learned that quantity does not equal quality – in fact I believe that the opposite is true; had I recruited any more participants the analysis might have been superficial with some of the quality lost and there might not have been equal representation of participants in the final themes.

Interview process

When interviewing some participants, I was pleased to hear that they had gained an increased understanding of their difficulties from being involved in clinical psychology training. However, I also noted feelings of frustration towards the mental health system, as evidenced below:

> *Having just interviewed another participant who mentioned that they were just rubberstamped in services, I feel really frustrated that they have had that experience. It makes me question my own clinical practice and whether I've ever withheld information from clients. I think there probably are times when I could have shared more about theory. However, I'm aware I need to put my clinical hat aside and act with my research hat. It's important I don't get caught up in this or I might miss other things in the data.*

I was glad to have reflected upon this at the interview stage as it meant that when I moved on to analysis I was aware of my own thoughts on this matter and tried not to let my emotional response impact on the data analysis. I

ensured I sent the codes and themes and subthemes to my supervisor to check this topic was prevalent enough to form a subtheme and was representative of what the participants said as opposed to being made a subtheme because I as the researcher felt it was an important issue. My supervisor concurred that this was a prevalent issue in the data and therefore it did form a subtheme, but engaging in this reflective process reassured me that this was not just due to my own feelings.

I had some reflections on what it was like to interview SUs on the course I was affiliated with, as evidenced below:

> *She at times said things such as "I shouldn't be telling you this". This made me reflect on my dual role as researcher and trainee. I wonder if there was information that was with-held from the interview because I am affiliated with the course? I wonder if this will be different when I interview those from other courses that I am not affiliated with? Although she did seem quite honest in her responses having also reflected on some negative experiences of involvement. This got me thinking more about my role as interviewer whilst also being a trainee. Also, what if she had had negative experiences with trainees – are people likely to tell me this considering I am a trainee and the trainees are my peers?*

Applying social identity theory, it is possible that this participant saw me as part of the "out group" which made her question whether or not she should be sharing information that was from the "in group". I was mindful to be receptive to what she was saying to encourage her to continue sharing information and she appeared to share more as the interview went on. This was easier as this particular interview was face-to-face meaning I could make use of non-verbal communication. However, it is impossible to say whether she might have shared more had I not been affiliated with the course or not been a trainee as well as a researcher. This is where it might have been beneficial for the researcher to be totally external to clinical psychology training.

Some participants tended to reflect on their involvement experience more widely and how this impacted on them, rather than just focusing on their experience of being involved in clinical psychology training. This made me

reflect on whether it is possible to isolate the personal effects of involvement to clinical psychology training:

> *This was a really difficult interview as he wanted to reflect a lot on experiences outside of his involvement on the clinical psychology training programme (e.g. writing a book, role at conferences) and I had to work hard to bring him back to talking about involvement in clinical psychology training. This was also similar to the participant I interviewed last week who talked a lot about being on a panel of experts outside of training. This got me thinking, is it possible to "box in" the personal effects to one particular experience (i.e. clinical psychology training?). It is likely that a combination of factors might have had a personal impact on individuals and by just homing in on clinical psychology training am I missing something in the journey of service users? Particularly in relation to recovery. Have my questions actually excluded other experiences which might be relevant?*

Although I had this reflection at the time, I do think it was important to keep the questions focused on clinical psychology training in order to meet the research aims. However, it might be said that future research could look at involvement more broadly, as many participants seemed to be involved in other areas as well as training. This links to another reflection I had after interviewing a different participant:

> *It seems that people are often involved in more than just clinical psychology training and I wonder if this means that training attracts a particular type of person who becomes involved in a lot of these initiatives? I wonder if my research will represent those who perhaps aren't involved in other groups, or whether it's an "all or nothing", where people are fully involved in several groups or not at all. I also wonder whether the personal impact runs wider than just being involved in clinical psychology training – they are likely affected by being involved in other groups too.*

After interviewing another participant, I had reflections on my dual role as a trainee clinical psychologist and it being difficult to put some of my clinical

interests aside in the role of the researcher who arguably should maintain a more neutral stance:

> *Was it just joining the service user group that had an impact or was it also to do with the therapy that the psychologist offered? Her answer sounded quite ACT (Acceptance and Commitment Therapy) focused in terms of living to your values of helping others. I found it difficult to step out of my clinical role and "put my research hat on" – there are so many things I would like to probe more about but do not want to sway them in any direction!*

However, there were other times whereby I feel the clinical skills I have developed helped me to glean more information from participants who were less forthcoming, and without my clinical training this might have proved more difficult:

> *I initially found it difficult to get him to expand on his answers to the first few questions. I feel like I had to think on my feet and really make use of the semi-structured nature of the interview to ask lots of follow up questions and use lots of summarising statements.*

I also had reflections on how as the interviews progressed it became difficult to isolate participants experiences from experiences I had heard about in previous interviews:

> *Did I prompt her too much when I asked about whether she looks at things in a different way? I don't know whether that question was too leading and I also wonder why I asked it? Was it because I've done eight interviews now and am aware of the themes that are coming up and so I'm trying to explore these further with this participant? I might need to be careful moving forward not to ask this question and let what comes up come up.*

After this reflection I chose to re-focus my attention on the semi-structured interview schedule and made the focus of any follow up questions relevant to what that particular participant had said rather than what previous

participants had said, therefore allowing for individual experiences to be better captured. However, there were still times when this was difficult, for example:

> *My asking of the question about a negative experience of involvement was definitely influenced by the answers given previously. I noticed myself saying "you might not be able to think of an example" because this was a common response in previous interviews. However, asking it in this way may have made it seem less "ok" to share negative experiences, almost like there was an expectation from me that she might not have had a negative experience. Interesting that I didn't frame the positive experience question in that way – maybe that says something about my views that service user involvement is positive and so there will obviously be positive examples. I need to be weary when analysing data and writing it up that I don't impose my own views about service user involvement being positive.*

This reflection was really important to hold in mind when analysing the data. I made a conscious effort to ensure I included aspects of participants experiences which were negative or had a negative impact as well as things which had a positive impact.

I also had reflections on how difficult it was when participants spoke of experiences which I have strong views on:

> *Towards the end of this interview he started mentioning not getting paid for some activities. I can't quite believe that some people are expected to work for no money! I think my beliefs about equality and fairness took over a bit here and I probed quite a lot about this, maybe more so than I would have done for other subjects. I was mindful of not pushing my judgements out there too much but on reflection some of my summaries may have come across like that (e.g. "that feels like it should be paid").*

It is possible that by expressing some of my own views this might have led this participant to mentioning more about this topic than he may have done otherwise. However, I also feel that this might have been helpful for the interview as by expressing some of my own views it might be said that I created

a sense of safety which enabled him to expand further on how this has affected him personally.

I encountered some difficulties with telephone interviews, particularly as I was unable to read participants facial expressions meaning it was difficult to know whether they were waiting for the next question or whether they were thinking of further answers. At times I feel I tended to move on to the next question when it is possible participants might have said more if they were given a little more time to think. Additionally, phone receptions were difficult on occasion, meaning I had to ask some participants to repeat what they said but this may have resulted in losing some of participants' original thoughts.

Conducting a telephone interview with a participant with a learning disability was particularly difficult, as I stated in my reflective diary:

> *It was difficult doing this interview over the phone because I could not pick up on non-verbal communication which I normally would rely more on with this population.*

I also reflected how it was difficult to keep the participant with a learning disability on topic, as he was keen to talk about his involvement in other areas:

> *I'm mindful I don't want to exclude his views from the analysis but I'm also mindful he talked a lot about other topics (not clinical psychology involvement) so I'm not sure how represented he will be in the findings.*

Analysis

When I first began analysis I felt it important to capture all aspects of the data:

> *It's really hard to capture all of the experiences of participants and I'm worried that I might miss some out meaning that participants have taken the time to tell me things which might not even feature in the research.*

After discussing this in supervision, I reminded myself of the deductive nature of the analysis and made a coding frame which helped me to consider the theories of interest alongside the data. This made it easier to count and discount data. However, I still felt guilty that participants had offered so much of

their time and spoke about their experiences and some of this data would not even be used. This also led me to questioning who the data was important to:

> *As I am not a service user myself, how do I know that what I am seeing as important in the data is actually important to them?*

This is a concept that I still struggle with and acknowledge that the research is actually my perception of the participants' perceptions and I might never truly be able to understand or convey their experience. However, I take comfort from the fact that aspects of the data that I have not privileged might be used in future research and I would hope that this might even be with increased SU involvement. I also acknowledge that this research is one of the first to explore service user experience of involvement in clinical psychology training and I hope that it will act as a springboard for future research.

Closing thoughts

Engaging in a process of reflection throughout the research has been helpful in learning more about myself and my philosophical standpoint. Having been through the research process I feel more confident in my research skills, particularly in relation to qualitative methodology. Finally, I feel I have been further able to reflect on the question of what classes as scientific evidence, and I feel strongly that qualitative research has an important role to play in the empirical evidence base.

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APPENDICES

Appendix A

Dear GATEKEPPERS NAME

I am a final year Doctorate in Clinical Psychology (DClinPsy) student at University of Nottingham on the Trent programme. I am conducting research into service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training; this has received full ethical approval from University of Nottingham. I am writing to ask if it would be possible for you to assist me in recruiting service user/carer representatives from your course at UNIVERSITY NAME.

The principle aims of the study are:

1. To use a qualitative approach to explore the experiences of service user/carer representatives involved in clinical psychology training.

2. To use psychological theory to develop an understanding of the personal effects of involvement.

Participants will be interviewed for up to an hour either face-to-face or via telephone.

To assist with recruitment, I would be grateful if you could forward on the attached recruitment advertisement to all service user/carer representatives on your course. I am obliged to advise that you should not exert any coercion on people to participate and I would anticipate that potential participants would contact me directly for more information or to complete the study.

Please feel free to contact me if you have any queries. Alternatively, you may wish to contact my supervisors Dr Anna Tickle (anna.tickle@nottingham.ac.uk) or Dr Danielle DeBoos (danielle.deboos@nottingham.ac.uk).

Many thanks for your help with this and I hope to hear from you soon.

Yours Sincerely,

Adam Hill

Trainee Clinical Psychologist

Adam.Hill@nottingham.ac.uk

Appendix B

I am a third-year student on the Trent Doctorate in Clinical Psychology course at University of Nottingham. For my research project, I am conducting a study to explore the experiences of service user/carer representatives involved in Clinical Psychology training, with a particular focus on understanding the personal effects involvement may have.

I am looking for participants who are currently/ were previously service user or carer representatives on a UK Doctorate in Clinical Psychology programme and have been so for at least six months. Participants will be interviewed about their experience either face-to-face or via telephone for up to approximately one hour.

If you meet the above criteria, I would be very grateful if you would be willing to take part in my study. As a thank you for taking part, you will get to choose a £10 gift voucher.

If you are interested, please contact me on the email address or telephone number below. If you do so, you will have the chance to find out more about the study before coming to any decision. You will be under no obligation to take part.

Many thanks for your time.

Kind regards

Adam Hill (3rd Year Doctorate in Clinical Psychology student at University of Nottingham)

Email: adam.hill@nottingham.ac.uk

Tel: 07591101632

Appendix C

PARTICIPANT INFORMATION

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title: Service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training

Researcher/Student: Adam Hill (adam.hill@nottingham.ac.uk or 07591101632)

Supervisor/Chief Investigator: Dr Danielle De Boos
(danielle.deboos@nottingham.ac.uk)

Dr Anna Tickle (anna.tickle@nottingham.ac.uk)

Ethics Reference Number: 0444

We would like to invite you to take part in a research study about service user/carer involvement in Clinical Psychology training. Before you begin, we would like you to understand why the research is being done and what it involves for you.

What is the purpose of this study?

The purpose of this study is to explore the experiences of service user/carer representatives involved in Clinical Psychology training, with a particular focus on understanding the personal effects involvement may have. The study also forms part of a Doctorate in Clinical Psychology qualification which the researcher is currently working towards.

Why have I been invited?

You have been invited because you are currently a service user or carer representative on a UK Doctorate in Clinical Psychology training programme.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You may change your mind about being involved at any time, or decline to answer a particular question.

You are free to withdraw at any point before or during the study without giving a reason. If you withdraw during the study we will not collect any further information about you or from you. However, we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To

safeguard your anonymity, we will use the minimum personally-identifiable information possible.

What will I be asked to do?

If you choose to take part, you will be asked to partake in an interview of up to approximately one hour whereby you will be asked questions about your involvement on the training programme and how involvement has affected you personally. You will also be asked to provide demographic information about yourself including your age bracket, gender, ethnicity, length of service user involvement, whether you are a service user or carer or both, course affiliated with, types of activities involved in, type of mental health service used (including whether you have previously accessed clinical psychology services), years since first use of services, whether you are still using services and years since last service use.

Interviews will take place either face-to-face at University of Nottingham or University of Lincoln, via telephone or via Skype.

Will the research be of any personal benefit to me?

We cannot promise the study will help you but the information we get from this study may help offer further insight into what both programme teams and service users might need to be aware of when entering into involvement initiatives, therefore better informing service user involvement in future.

For taking part in the study, you will also receive a £10 gift voucher of your choosing from a set number of options. You will be asked to choose this in advance of participation and if you elect to a face-to-face interview this will be given to you on the day of interview. If you elect for a telephone or Skype interview, you will have a choice of the gift voucher being posted to the University department you are affiliated with, your home address or you can collect from University of Nottingham. Your home address details would only be used for this purpose and then securely destroyed.

Are there any possible disadvantages or risks in taking part?

It is not anticipated that there will be any major disadvantages or risks in taking part. The interview topics will focus on how involvement has personally affected you and this may necessitate some reflection on your mental health. However, it is up to you how much you share. If the interview causes any distress, it can be terminated at any time. Furthermore, if you feel distressed as a result of something discussed in the interview, you are encouraged to talk to a member of the research team who will be able to signpost you to appropriate resources. Information about how to access resources which may be of help are listed at the end of this participant information sheet.

What will happen to the information I provide?

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

Face to face, telephone and Skype interview data will be audio recorded on an encrypted audio recorder device and later transcribed by the researcher or by an approved external transcription service. Where possible information about you which leaves the University will have your name and personal details removed and a unique code will be used so that you cannot be recognised from it. It will also be ensured that any external transcription service used has a secure system for data transfer, access, and storage – to maintain data confidentiality. They will also be asked to sign a Transcriber Confidentiality Agreement. After transcription, the transcripts of your interview will be uploaded into a password-protected database and analysed by the researcher.

We would like to be able to quote what you say in our report or a publication. We will make sure that your anonymity is protected and will not report any demographic information which may lead to you being identified. But if you do not wish us to do so, please tell us. The research will be written up into a thesis for the researcher's qualification, presented in poster form at a conference and submitted to an academic journal for publication. If you wish to know the results of the study and to receive an executive summary, please indicate how you would like this information to be sent to you on the consent form.

We will follow ethical and legal practice and all information will be handled in confidence.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

At the end of the project, all raw data will be kept securely by the University under the terms of its data protection policy after which it will be disposed of securely. The data will not be kept elsewhere
If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the email addresses above.

What if there is a problem?

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee adrian.pantry1@nottingam.ac.uk who will pass your query to the Chair of the Committee.

Support services

Accessing mental health services:

As a first port of call, you can visit your GP for any health concerns you have. If you are not registered, you can use the NHS choices tool to find a local practice:

https://www.nhs.uk/Service-Search/GP/LocationSearch/4

Psychological therapies:

If you are looking for NHS-run psychological therapies (also called talking therapies or 'IAPT'/'Improving Access to Psychological Therapies': this includes therapies such as counselling, psychotherapy, cognitive behavioural therapy) you can look for your local psychological therapies using the online NHS choices 'find psychological therapies' tool:

https://www.nhs.uk/Service-Search/Psychological%20therapies%20(IAPT)/LocationSearch/10008

Crisis support

If you feel like you are experiencing a mental health crisis (e.g. your mental health is at breaking point and you feel you might endanger yourself or others) medical help is vital and can be obtained by calling 111 or 999 in an emergency. More information about crisis support can be found at:

https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/accident-emergency-ae/#.XZdWz0ZKiM8

Listening and emotional support services

The Samaritans are a listening service available to help people talk through their emotions and to provide confidential, non-judgemental support. They can help people with difficult feelings who want to talk to someone immediately.

www.samaritans.org.uk

Helpline: 116 123 (free)

Email: jo@samaritans.org

Open 24/7

Appendix D

PARTICIPANT CONSENT

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title: Service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training

Researcher: Adam Hill (adam.hill@nottingham.ac.uk)

Supervisor: Dr Danielle De Boos (danielle.deboos@nottingham.ac.uk)

Dr Anna Tickle (anna.tickle@nottingham.ac.uk)

Ethics Reference Number: 0444

- Have you read and understood the Participant Information? YES/NO
- Do you agree to take part in an interview about personal effects of involvement in clinical psychology training which will be recorded and transcribed by an external transcription company?

YES/NO

- Do you know how to contact the researcher if you have questions about this study?
  YES/NO
- Do you understand that you are free to withdraw from the study without giving a reason?
  YES/NO
- Do you understand that once you have been interviewed it may not be technically possible to withdraw your data unless requested within one week?
  YES/NO
- Do you give permission for your data from this study to be shared with other researchers in the future provided that your anonymity is protected?
  YES/NO
- Do you understand that non-identifiable data from this study including quotations might be used in academic research reports or publications?
  YES/NO
- Do you wish to be sent a copy of an executive summary containing the results
  YES/NO
  upon completion of the research?*
- I confirm that I am 18 years old or over
  YES/NO

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* If you answered yes to wanting an executive summary of the research, please provide your postal address or email address below so this can be sent to you:

……

Signature of Participant …… Date ……..

Name (in capitals) ……

Appendix E

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
Division of Psychiatry and Applied Psychology
The University of Nottingham
YANG Fujia Building
Jubilee Campus
Nottingham
NG8 1BB
t: +44 (0)115 82 32214

www.nottingham.ac.uk/medicine

Investigators: Adam Hill and Danielle De Boos

Title of study: Service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training.

Ethics reference number: 0444

Friday 22nd November 2019

A favourable opinion is given to the above named study on the understanding that the applicants conduct their research as described in the above numbered application, and adhere to all conditions under which the ethical approval has been granted and use only materials and documentation that have been approved. If any amendments to the study are required, an amendment should be submitted to the committee for approval.

David Daley

David Daley (Professor)

Co-Chair of DPAP Ethics Subcommittee

Amanda Griffiths

Amanda Griffiths (Professor)

Co-Chair of DPAP Ethics Subcommittee

University of Nottingham
UK | CHINA | MALAYSIA

DPAP Committee

14/02/2020

Supervisor: Danielle De Boos

Applicant : Adam Hill

Project: Project Id Service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training

A favourable opinion is given to the above named study on the understanding that the applicants conduct their research as described in the above numbered application. Applicants need to adhere to all conditions under which the ethical approval has been granted and use only materials and documentation that have been approved.

If you need to make any any changes (for example to the date or place of data collection, or measures used), an Amendment Form should be submitted. This can be done by the Supervisor in 'Create Sub Form' in the Actions Menu on the left hand side of the page on the on-line system: Select 'Amendment Form'

yours

David Daley

Professor David Daley

Co-Chair of DoPAP Ethics Subcommittee

Amanda Griffiths

Professor Amanda Griffiths

Co-Chair of DoPAP Ethics Subcommittee

Appendix F

1. What led you to become involved in clinical psychology training?
2. In what ways are you involved in clinical psychology training?
3. Has your involvement in training led to any changes in the way you see yourself?
    a. [if yes] What has led to this?
    b. [if yes] How does this differ to the way you seen yourself when you began involvement?
4. Do you feel like you have a sense of control and influence over the involvement activity that you are doing? To what extent?
    a. Can you give me some examples?
5. Has your experience of involvement influenced your sense of control in other areas of your life?
6. Can you give a specific example of a positive experience of involvement, when something went really well?
    a. How did that experience impact you personally that day? Weeks later?
    b. Does it still have an impact on you now, and if so how?
7. Can you give a specific example of a negative experience of involvement, when something did not go so well?
    a. How did that experience impact you personally that day? Weeks later?
    b. Does it still have an impact on you now, and if so how?
8. Can you think of a specific experience of involvement that has had an impact on your mental health?
    a. Did this impact on your involvement moving forward and if so, how?
9. How well supported do you feel in relation to your involvement?
    a. Is there anything missing from your support network?
10. Can you tell me about how you've experienced being part of a group of involved service users and carers?
    a. Are there any dynamics within the group that have impacted on you personally or your ability to undertake involvement work?

PROBES

- Can you tell me about a specific example of this in your involvement work?
- Can you tell me more about that?
- Why do you feel that way?
- What do you mean by that?
- Minimal encouragers (i.e. nodding)
- Paraphrasing and summarising

Appendix G

Power

What types of power are referred to?

Decision making power? – A gets B to do something

Non-decision making power? – Directly and indirectly influence behaviours of others e.g. agenda setting

Ideological power? – Believe the decisions are their own, but constrained by society/system meaning they can't fathom other options

French and Raven bases of power:

Legitimate – Responsibility tied to appointed/elected position, the power is legitimate

Reward – compensation for compliance e.g. money, time, praise

Coercive – power to punish or potentially punish

Referent – influence over people due to "likeability", charisma, good relationships (people looking up to others)

Expert – E.g. High level of education/skills/knowledge/experience. People look to you to bring in your expertise and make a decision.

Informational – A person's ability to control information that others need to accomplish something. Power not in the information itself, but from being in a position to share, withhold, distort, manipulate or conceal it. Information shouldn't be held onto if it can help others – should be shared, doesn't belong to a person.

Social identity

Do participants see their identity as being grounded in the group to which they belong (e.g. service user) – social categorisation. Or not?

Do participants talk about in-group or out-group regarding service users, trainees and professionals? Do they discriminate against the out-group?

Are differences between groups and similarities within the group exaggerated? (to enhance identity)?

Do participants report having a "fluid" identity? (e.g. does their perception of themselves change as identification with different social groups becomes more/less salient?)

Recovery

CHIME recovery framework –

Connectedness

- Peer support and support groups

- Relationships
- Support from others
- Being part of the community

Hope and optimism about the future

- Belief in possibility of recovery
- Motivation to change
- Hope-inspiring relationships
- Positive thinking and valuing success
- Having dreams and aspirations

Identity

- Dimensions of identity
- Rebuilding/redefining positive sense of identity
- Overcoming stigma

Meaning in life

- Meaning of mental illness experiences
- Spirituality
- Quality of life
- Meaningful life and social roles
- Meaningful life and social goals
- Rebuilding life

Empowerment

- Personal responsibility
- Control over life
- Focusing upon strengths

<u>More general recovery</u>

Do participants describe:

Subjective nature

Re-engagement with life

Improved coping

Restoration of sense of self

Restoration of sense of purpose

Yalom's 11 curative factors

When talking about each other and belonging in the group, do they or do they not refer to:

1. Installation of hope

Optimism re: future and ability to cure what need not be endured and endure what need not be cured

2. Universality

Not alone with problems

3. Imparting of information

Educates & empowers group members with knowledge pertaining to their specific situation

4. Altruism

Help somebody else means feeling useful. Increased self-worth and confidence

5. Corrective recapitulation of primary family group

Rectification of past family/childhood events within group, substitute family, new ways of relating, weakening unhelpful patterns

6. Development of socialising techniques

Advances relating/social skills e.g. tolerance, boundaries, empathy, conflict resolution

7. Imitative behaviour

Witnessing other members who function more adequately

8. Interpersonal learning

Openly sharing and communicating and receiving support and respective feedback

9. Group cohesiveness

A sense of belonging, acceptance and value

10. Catharsis

Opportunity of expression of strong affect

11. Existential factors

Understanding and accepting reality of the human condition. Accept life without seeking escape or denial

Appendix H

Power/empowerment

Does the data show evidence for or against…

- Being able to make own decisions (decision making power) – Lukes' dimensions of power
- Being able to make decisions but based on an agenda (non-decision making power) Lukes' dimensions of power
- Believing decisions are their own, but being constrained by the society or system preventing fathoming other options (ideological power) Lukes' dimensions of power
- Taking personal responsibility CHIME framework - empowerment
- Having control CHIME framework - empowerment
- Focusing on and using strengths CHIME framework - empowerment
- Exertion of reward power (e.g. being paid) French and Raven's bases of social power
- Exertion of expert power (e.g. are they being looked to for information based on their expertise? Or conversely, does the expert power of the clinical psychologist outweigh the service user power?) French and Raven's bases of social power
- Exertion of legitimate power (e.g. power is legitimate because of the title/elected/appointed) French and Raven's bases of social power
- Exertion of informational power – is information freely shared? French and Raven's bases of social power

Identity

Does the data show evidence for or against….

- Dimensions of identity (i.e. more than one identity) CHIME framework – identity
- Rebuilding or redefining a positive sense of identity CHIME framework – identity
- Overcoming stigma CHIME framework – identity
- Participants grounding their identity in a group to which they belong? Social identity theory
- Referring to in-group or out-group and identifying differently to these? Social identity theory
- Exaggerating similarities within group and differences between groups? Social identity theory
- Having a fluid identity (e.g. self perception changing depending on whether identification with different social groups becomes more/less salient?) Social identity theory
- Restoration of sense of self - CHIME framework – identity
- Restoration of sense of purpose - CHIME framework – identity

Connectedness

Does the data show evidence for or against….

- Offering or accepting peer support within the group – CHIME framework – connectedness
- Openly sharing and communicating and receiving support and respective feedback - CHIME framework – connectedness
- Being part of the wider programme/ wider community - Social identity theory
- A sense of belonging, acceptance and value – Yalom – Group cohesiveness
- Feeling useful for helping others (altruism) – Yalom - Altruism
- Not being alone with problems – Yalom – Universality
- Better social skills to relate to others (e.g. tolerance, boundaries, empathy, conflict resolution) – Yalom – socialising techniques

Meaning in life

Does the data show evidence for or against….

- Optimism about the future with or without mental health condition – Yalom – installation of hope
- Attaching meaning to mental health experiences – CHIME framework – meaning in life
- A difference in quality of life - CHIME framework – meaning in life
- A meaningful life and social roles - CHIME framework – meaning in life
- A meaningful life and social goals - CHIME framework – meaning in life
- Rebuilding life - CHIME framework – meaning in life
- Re-engagement with life - CHIME framework – recovery
- Positive thinking and valuing success - CHIME framework – hope and optimism about the future
- Having dreams and aspirations - CHIME framework – hope and optimism about the future
- Belief in possibility of recovery - CHIME framework – hope and optimism about the future
- Motivation to change- CHIME framework – hope and optimism about the future

Appendix I

CASP
Critical Appraisal Skills Programme

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CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ✓ | Can't Tell | No

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments: The following aims were stated: The present study therefore aims to build on previous findings by specifically exploring the personal effects that involvement may have on service user/carers and by deductively applying psychological theory to help explore and understand the personal effects of involvement on service users/carers. This will help to inform future involvement in clinical psychology training and help shift the focus to considering how best to optimise involvement for service user/carers as well as trainees. It might also help those considering involvement to make informed choices about whether and how to become involved, based on an understanding of other people's experiences of the personal impact.

2. Is a qualitative methodology appropriate?

Yes ✓ | Can't Tell | No

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments: The research question in this project was 'what are service users'/carers' experiences of the personal effects of involvement in clinical psychology training?'. The exploratory nature of the research with a focus on experience makes a qualitative methodology appropriate. This is due to the interest in individual meaning and seeing experience in context, as opposed to seeking to test hypotheses by controlling variables and identifying relationships between variables or gathering numerical data which would be more suited to a quantitative methodology.

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ✓ | Can't Tell | No

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: TA is an approach which can span across theoretical and epistemological stances (Braun & Clarke, 2006). This makes it a flexible approach capable of delivering a detailed, rich and complex account of data for almost any qualitative research question (Braun & Clarke, 2013) - in this instance it would seem appropriate to address service user/carers' experiences of the personal effects of involvement in clinical psychology training. A deductive analysis is more analyst driven, meaning the analysis may be driven by the researcher's theoretical or analytic interest (Braun & Clarke, 2006). A deductive approach to TA therefore seemed useful for the present research, with theoretical propositions informing the analysis (Yin, 2014), with a specific focus on theories relating to potential personal effects of SUI (e.g. power, identity, recovery).

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4. Was the recruitment strategy appropriate to the aims of the research?

Yes	✓
Can't Tell	
No	

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: **Purposive sampling was appropriate to recruit service user representatives from doctorate in clinical psychology courses which enabled exploration into their experiences. Not all service users took part and this means not all experiences are accounted for - additionally carers are under-represented. No participants were recruited via snowballing meaning the experiences of those no longer involved are also not represented.**

5. Was the data collected in a way that addressed the research issue?

Yes	✓
Can't Tell	
No	

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments: **Semi structured interviews allow exploration into experiences. The interview questions enabled exploration into the theories of interest but the flexible nature of the interview also allowed for other aspects of experiences to be captured. Audio recordings were made which were transcribed. There were no novel findings by interview 14, suggesting data saturation.**

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6. Has the relationship between researcher and participants been adequately considered?

Yes ✓
Can't Tell
No

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments: The main researcher (a trainee clinical psychologist) approached this research from the position of somebody who is on the receiving end of the training and involvement that service users/carers provide. The researcher was also mindful of their professional employment which may have influenced how service users/carers interacted with them compared to a peer researcher. The researcher held a shared language (clinical psychology) that service users/carers were aware of which may have also influenced how they spoke about particular experiences. The research should therefore not be considered as "giving voice" to the service users as ultimately the research was conducted and written by a non service user representative which may mean certain aspects of the research were privileged over others.

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ✓
Can't Tell
No

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments: Approval was sought by the ethics committee and ethical considerations relating to informed consent, right to withdraw, confidentiality, data management and risk of harm were all considered in the design of the study and throughout. Participants were provided with a list of potential avenues for support.

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Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: The research findings are discussed alongside previous research and adds to it as experiences across multiple training programmes are now evidenced. Current practice is considered (e.g. on how to address power imbalances, renumeration, how to create a psychologically safe environment for service users). The research findings might also be used to enhance services e.g. by sharing more theoretical information. Further research is recommended, particularly to capture the experiences of those no longer involved and carers.

Service user and carer representatives' experiences of the personal effects of involvement in clinical psychology training

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Trent Doctorate in Clinical Psychology

Background

Extant literature has predominantly focused on evaluating and optimising service user (SU) involvement for the benefit of clinical psychology trainees.

Only recently has research started to consider the effects involvement may have on SUs, with benefits including feeling valued and heard[1], increased confidence and assertiveness[2] and developing a powerful sense of self[3], and challenges including power struggles[4] and feeling daunted[2] and invalidated[3].

Previous research has derived samples from singular training programmes. Exploring SUs' experiences from multiple programmes seemed the logical next step.

Concepts highlighted as important in the SU involvement literature related to power, recovery, identity and group development were explored via the application of psychological theory.

Aims

- To explore the personal effects that involvement in clinical psychology training may have on SUs/carers
- To deductively apply psychological theories of power, recovery, identity and group development to help explore and understand the personal effects of involvement

Method

Design
A qualitative approach was taken to the research.

Participants
Purposive sampling of individuals who were involved in clinical psychology training as a service user or carer representative for at least six months.

Data collection
Individual semi-structured interviews were conducted with participants either face-to-face or via telephone.

Procedure
Demographic information was gathered . Four interviews were conducted face-to-face (at the researcher's University) with the remaining ten conducted via telephone.

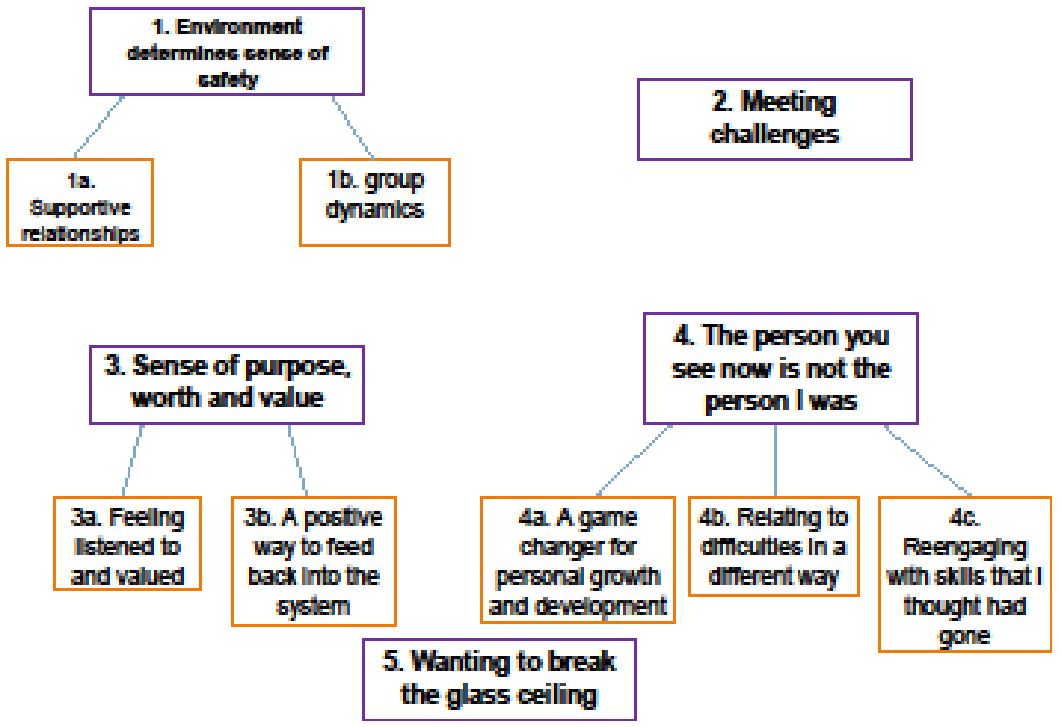
The semi-structured interview schedule contained non-directive, open ended questions aimed at gathering detailed data grounded in participants' experiences of personal motivations for becoming involved in clinical psychology training; what involvement entails; and whether and how involvement links to SUs' self-perception, identity and sense of empowerment.

Data Analysis
Transcribed interview data was analysed using Thematic Analysis based on the principles suggested by Braun and Clarke[4]. A deductive approach to data analysis was taken, with theoretical propositions informing the analysis, with a specific focus on theories relating to potential personal effects of SUI (e.g. power, recovery, identity, group development). All data (both confirmatory and disconfirmatory) related to the theories was analysed.

Results

Recruitment
Fourteen people were recruited, of which twelve identified as SUs and two as SUs and carers. Four interviews were conducted face-to-face, with the rest via telephone.

Themes and subthemes



The findings suggest it is important that the environment in clinical psychology training fosters psychological safety for SUs, via positive and supportive relationships with trainees and staff, in which SUs are treated as equal colleagues and financially reimbursed as such.

Identified benefits for SUs included feeling a sense of purpose, worth and value and a positive change in self-perception, including re-engaging with lost skills. Findings suggest involvement can offer an opportunity to further develop recovery. However, there were reported difficulties in joining a new SU group including group dynamics and power imbalances.

Findings also suggest that there is a glass ceiling to involvement which SUs have a desire to break.

Discussion

The described benefits of involvement tied in with the CHIME framework [5], including empowerment, a sense of connection, improvement in meaning and quality of life and hope and optimism about the future. Many of these experiences led participants to indicate they had developed a positive sense of identity including overcoming felt stigmas as a result of involvement. Therefore, whilst not its explicit aim, involvement can offer an opportunity to further develop recovery, sometimes beyond what has been achievable within services.

Feeling valued seemed to be contingent on feeling listened to and staff not exerting expert power [6] by overruling SUs and allowing SUs to hold decision-making power [7]. Less value was felt when decisions were already made by professionals, implying that there can be times where professionals exert non-decision-making power by controlling agendas [8]. This reported power dynamic within clinical psychology training adds to previous findings that almost all involvement can lead to empowerment [9] or disempowerment [10] but goes further by considering the types of power at play. SUs and professionals should explore the intricacies and nuances of managing and sharing power to enable SUs to feel valued and reap benefits from involvement, including developing a positive sense of identity.

A limitation is only two participants identified as carers (and they also identified as SUs) therefore carers experiences are under-represented. The research also failed in attempts to recruit SUs who were no longer involved, and thus whose experiences might differ. Future research should focus on these areas.

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SMALL-SCALE RESEARCH PROJECT

A service evaluation of a six-session mindfulness group for those with intellectual disabilities

Abstract

This service evaluation evaluated a six-session mindfulness group for five individuals with intellectual disabilities to determine if the group was effective at increasing mindfulness and reducing anxiety, and whether replication was feasible. The GAS-ID and PHLMS were administered pre and post-group. Two participants demonstrated statistically reliable reduction in anxiety, with one showing clinically significant change. No participants demonstrated a statistically reliable change on their PHLMS awareness subscale scores, whilst two participants achieved a statistically reliable reduction in their PHLMS acceptance scores. Correlation analyses revealed greater reductions in anxiety were associated with greater increases in awareness. Statistical results regarding mindfulness cannot be relied upon due to the PHLMS not appearing suitable for this population. Qualitatively, participants reported reduced anxiety and increased mindfulness, with some relating using mindfulness with reduced anxiety. It would be feasible to deliver this group again as it had some positive benefits, high participant engagement, acceptability of mindfulness exercises, good adherence to session plans and is resource efficient.

Key Words

Anxiety, Intellectual Disabilities, Mindfulness, Service evaluation

Introduction

Mindfulness

Mindfulness has its roots in spiritual traditions. It places focus on conscious attention and awareness, with mindfulness being defined as “the state of being attentive to and aware of what is taking place in the present” (Brown and Ryan, 2003). It is suggested that there are two components to mindfulness; firstly, paying attention to the moment and secondly, being curious, open and accepting of one’s experience in the moment (Bishop et al., 2004). Mindful practices have been adapted for use in Western societies and incorporated into psychotherapeutic approaches (Felder et al., 2012). Examples include mindfulness-based cognitive therapy, mindfulness-based stress reduction and dialectical behaviour therapy.

Using mindfulness to focus on current experience and functioning contrasts with individuals’ usual habitual or automatic functioning (Brown and Ryan, 2003). Focusing on the present moment can therefore play a key part in helping individuals to disengage from automatic thoughts, habits and behaviour patterns, thus helping individuals self-regulate their behaviours (Ryan and Deci, 2000). Engaging in mindfulness has also been linked with increased pleasure, with LeBel and Dube (2001) finding that individuals focused on the sensory experience of eating gained more pleasure than those who were engaged in a distraction task whilst eating. Engaging in such higher quality moment-to-moment experiences is associated with increased wellbeing (Brown and Ryan, 2003), therefore demonstrating benefits of utilising mindfulness in day-to-day life.

It has been suggested that in mindfulness it is the processes of decentering, acceptance, exposure and self-regulation (Allen et al., 2006; Baer, 2003; Bishop et al., 2004; Chambers et al., 2008; Hooker and Fodor, 2008; Hayes and Feldman, 2004; Thompson and Gauntlett-Gilbert, 2008) which enhance psychological wellbeing. Decentering occurs due to the detached nature of observing internal experience, allowing thought content to be monitored without judgement. Thought acceptance occurs by not labelling thoughts as “good” or “bad” or seeking or avoiding thoughts. Therefore, previously suppressed thoughts can enter one’s awareness. It has been suggested that the repeated exposure to distressing

thoughts leads to desensitisation and therefore reduced emotional reactivity (Haydicky, 2010). Therefore, experiential avoidance may be reduced, a concept associated with mental health difficulties (Chawla and Ostafin, 2007). By utilising mindfulness exercises and therefore maintaining a detached observation, individuals are given the opportunity to identify problematic situations and utilise coping strategies without responding habitually, reducing impulsivity. All this combined may lead to self-regulation of attention, cognition and emotion, enhancing psychological wellbeing.

The efficacy of mindfulness-based interventions (MBIs) is moderate-to-strong at reducing anxiety and depression (Hofmann et al., 2010; Khoury et al., 2015; Khoury et al., 2013). However, as MBIs consist of many components with mindfulness intertwined, questions still arise as to whether mindfulness is the active component which leads to change, and therefore whether standalone mindfulness interventions can be effective at reducing mental health difficulties. A meta-analysis by Blanck et al. (2018) found that standalone one-to-one mindfulness interventions based on Bishop et al.'s (2004) mindfulness definition had a small-to-medium effect at reducing anxiety and depression symptoms. This suggests that it may not be necessary to embed mindfulness into a wider therapeutic approach to be beneficial. However, there were no clinical samples in the meta-analysis, limiting generalisability to clinical populations.

There is an increasing evidence base for using mindfulness clinically. Evidence suggests mindfulness interventions are successful for various client populations including children (Burke, 2010), adolescents (Biegel et al., 2009) and individuals with intellectual disabilities (ID) (Singh et al., 2007).

Mindfulness for individuals with ID

Mindfulness exercises for those with ID include the 'Soles of the Feet' exercise (Singh et al., 2003), which involves individuals shifting their attention from distressing thoughts to a neutral body part – the soles of their feet. This exercise has been found to be beneficial in helping those with moderate ID to manage their distress, thus avoiding placement breakdown (Singh et al., 2007).

It has been suggested that mindfulness may be an effective approach for those with ID because the activities are experiential, meaning they do not

necessitate more sophisticated verbal reasoning skills which some psychotherapies warrant (e.g. CBT) (Brown and Hooper, 2009). However, to maximise effectiveness, there is continued need to adapt mindfulness exercises for those with ID (Robertson, 2011).

There is evidence to suggest effectiveness of using mindfulness-based interventions with those with ID in group settings. Idusohan-Moizer et al. (2015) evaluated a mindfulness-based cognitive therapy group and found that participants reported multiple gains which were maintained at follow-up, the most significant being reduced anxiety. However, it was not clear which therapy components were most effective at eliciting change. It cannot therefore be concluded whether it was the mindfulness aspect which led to improvements.

Yildiran and Holt (2015) interviewed six participants from a mindfulness group, with the thematic analysis indicating that those with ID could understand mindfulness and benefitted from the intervention. However, the researcher held a joint role of facilitator and interviewer, meaning socially desirable answers cannot be ruled out. In addition, the group combined mindfulness with relaxation, meaning it is not known whether participants would report similar benefits for a mindfulness group without relaxation.

Rationale and objectives

Psychology within the Community Learning Disabilities Team (CLDT) offers one-to-one mindfulness interventions to adults with ID who are experiencing anxiety and distress. There are local drivers for group-based mindfulness provision to streamline resources and reduce psychology waiting times. However, it is not yet known whether a group-based provision would be feasible (regarding cost, time, delivery, attendance) and effective at reducing anxiety symptoms in a group setting. Considering the literature discussed, there is a need to evaluate groups which solely focus on mindfulness techniques to discover whether this provision is effective at reducing distress for those with ID.

There are also national drivers to offering group-based provision for those with ID, in relation to broader policy around fostering self-management and ensuring an equal access to services for this population (Burke, 2014). In adult mental health services group-based psychological interventions based on mindfulness are

available, however no such provision is currently available to those with ID within the CLDT.

In designing the group evaluated in this study, it was decided that mindfulness exercises would be taught and practiced as opposed to a structured therapeutic programme being delivered. This decision was in part due to Blanck et al.'s (2018) finding that standalone mindfulness interventions are effective at reducing anxiety. In addition, after discussion with day-centre staff it was decided that those partaking in the group may have found a more sophisticated therapy programme (e.g. mindfulness-based CBT) difficult.

Considering the above, the service evaluation aims to address:

1. Is teaching mindfulness skills in a group setting (a mindfulness-based group intervention) effective at reducing self-reported symptoms of anxiety in those with ID?

2. a) Do participants report an increase in mindfulness skills having attended the group?

2. b) Is the active ingredient of the group (mindfulness) related to the targeted outcome (reduced anxiety) of the group?

3. Is it feasible for this group to be implemented as a regular offering from the CLDT service?

Method

This service evaluation evaluates a six-session weekly mindfulness group which taught and practiced several mindfulness exercises. The group was held at a local day-centre for people with ID.

Facilitators

The group was facilitated by a trainee Clinical Psychologist and an Assistant Psychologist. Both were experienced using mindfulness-based interventions and had engaged in extensive reading in the area. The facilitators were supervised by a Clinical Psychologist who was experienced in mindfulness-based interventions. The sessions were planned and delivered equally by each facilitator. Two day-centre staff supported participants each session.

Participants

The local day-centre manager referred seven clients to the CLDT who she identified as experiencing anxiety. They were approached by the facilitators and consented to group participation and for their data to be used in a service evaluation. Six participants scored above the clinical cut-off on the Glasgow Anxiety Inventory (GAI) prior to the group. The participant who did not reach the cut-off score still participated in the group; however their scores were not used in this evaluation. One participant did not complete the group; therefore five participants' data were used in the evaluation (two females, three males, age range 21 – 62, mean= 40.2, *SD*= 15.49). All participants had a mild ID diagnosis and were not undergoing any other anxiety treatment.

Procedure

The project received local ethical approval from the trust's research department.

At a one-to-one pre-group session with a facilitator, participants were given verbal and easy-read information about mindfulness, the group and the service evaluation. Participants were given the opportunity to ask questions before they gave written consent to partake in the group and for their data to be used in a service evaluation (all participants were deemed to have capacity). Their right to withdraw at any time was explained. Participants were then invited to complete the Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) and the Philadelphia Mindfulness Scale (PHLMS) pre-group outcome measures. The aim was for day-centre staff to administer these, however due to staff shortages they were completed with the facilitators who read out the questions. Visual resources were used to assist participants giving a response.

Group structure and content

Six approximately one-hour sessions were run on consecutive weeks. Exercises facilitated learning and practicing mindfulness skills, with brief reflection periods, as well as setting and reviewing homework tasks. Participants were also asked to reflect upon when they might use their mindfulness skills to prompt them to do this in distressing situations. The mindfulness activities selected followed Bishop

et al's (2004) mindfulness definition and therefore allowed for practice of acceptance and present moment awareness skills.

An adapted soles of the feet exercise (Singh et al., 2003) was used in the group to make it more accessible, with participants being asked to focus on the palms of their hands instead. The emotional response focused on was anxiety. The two other exercises (mindful observation of thoughts and the five senses exercise) were adapted from a skills training guide for people with ID (Ingamells and Morrissey, 2014). An adaptation was made to the mindful observation of thoughts exercise, whereby individuals imagine their thoughts as passing clouds. Participants could instead write down their thoughts on paper clouds to make the activity less abstract and aid with imagination.

Session one was dedicated to group rules and developing belonging, with the remaining sessions teaching mindfulness skills. Session six was used as a recap. Topics covered in each session are given in Table 6. Post-group measures were administered after session six by the group facilitators.

Table 6. Outline of each session

Session Number	Topics covered
1	Introductions
	Group rules
	Drawing faces and sticking on flip chart to develop sense of belonging
	Introducing the concept of mindfulness
2	Recap concept of mindfulness
	When mindfulness can help
	Soles of the feet practice 1
	Homework (practice soles of the feet when feeling distressed)
3	Review homework and barriers
	Soles of the feet practice 2
	Introduce mindfulness log
	Mindful observation of thoughts practice 1
	Homework (complete mindfulness log)
4	Review homework
	Mindful observation of thoughts practice 2
	Five senses exercise practice 1
	Homework (being mindful of reactions to difficult situations)
5	Review homework
	Five senses exercise practice 2
	Reflecting on feelings before and after mindfulness exercises
	Homework (log of feelings after completing mindfulness exercises)
6	Review homework
	Re-cap sessions 1-5, with one more practice of each mindfulness exercise
	Informal feedback
	Issuing of certificates

Service evaluation design

Glasgow Anxiety Scale for people with an Intellectual Disability. The GAS-ID (Mindham and Espie, 2003), a 27-item questionnaire which measures anxiety in those with ID, has a clinical cut-off of 15 or above. The GAS-ID demonstrates very high test-retest reliability (*r*=.953), high internal consistency (Cronbach's alpha=.96) and strong criterion validity (*r*=.72) assessed using Beck's Anxiety Inventory (Beck et al., 1988). The questionnaire was administered pre and post-group, with change scores used to address aim 1.

Philadelphia Mindfulness Scale. The PHLMS (Cardaciotto et al., 2008) is a bidimensional measure of two key mindfulness components– present-moment awareness and acceptance. 20 items require a five-point Likert scale response (never-very often), giving scores for awareness and acceptance sub-scales (10 items each). Use of total scores is not recommended as the two sub-scales are un-correlated (Park et al., 2013). The PHMLS demonstrates respectable internal consistency for both the awareness (Cronbach's alpha= .75) and acceptance (Cronbach's alpha= .75) sub-scales. The awareness subscale had strong construct validity with the KIMS Observe subscale (*r*= 0.83), and the acceptance subscale had strong construct validity with the KIMS Accept without Judgement subscale (*r*= 0.79) (Park et al., 2013). Test re-test reliability was not reported for an ID population.

The PHLMS was administered pre and post-group with to address aim 2a. Although validated on a non-ID population, the PHLMS was used as there are no mindfulness measures developed for those with ID.

In order to address aim 2b, participants change scores on the GAS-ID were correlated with their change scores on PHLMS awareness and acceptance subscales.

The Change Interview. The Change Interview (Elliott et al., 2001) is a qualitative interview administered at the end of therapy and includes eight open-ended questions about the client's change perception, change attributions and helpful and non-helpful aspects of therapy. It was administered post-group to ascertain whether

participants identified any changes and their attribution of change. This helped address aims two and three.

Competency and adherence measure. A competency measure was adapted by the facilitators based on Chawla et al.'s (2010) original measure. Adherence measuring consisted of ticking off sections of the session plan which were completed. Post-session each facilitator rated the other on session delivery and to what extent mindfulness techniques were used. Group participants also rated each session on content, delivery and understanding.

Feasibility. To address aim 3, feasibility was operationalised, enabling it to be measured. The feasibility indicators and how these were measured are outlined in Table 7.

Table 7. Measures of feasibility.

Feasibility Indicator	Measurement
Resources	Session preparation time
	Staff hours utilised
	Room availability and suitability
Participant engagement	Attendance records
	Retention rates
	Observations in session
Acceptability of outcome measures	Observations when administering each measure
	Items missed on each measure
Adherence to session plan/intervention	Competence and adherence measure
	Participant session rating scales
	Observations in session
Acceptability of mindfulness exercises	Change interview
	Observations in session

Results

Descriptive statistics

Table 8 shows the scores on the GAS-ID and PHLMS for the five participants who completed the group. Participant 2 missed session three due to illness.

All participants in the evaluation scored at or above the clinical cut-off for anxiety (15) pre-group. Four participants reported a reduction in anxiety symptoms on the GAS-ID post-group compared to pre-group. One participant's score remained the same.

Table 8. Descriptive statistics.

		GAS-ID		PHLMS Awareness		PHLMS Acceptance	
Participant	Sessions attended	Pre-group score	Post-group score	Pre-group score	Post-group score	Pre-group score	Post-group score
1	6	29	14	24	27	32	34
2	5	22	18	36	30	46	35
3	6	15	15	29	24	29	34
4	6	15	7	23	18	25	16
5	6	15	9	33	30	26	30

The higher the score on the PHLMS awareness and acceptance subscales, the more awareness and acceptance that individual has. Scores on the PHLMS awareness subscale increased for one participant post-group compared to pre-group, whilst the other four reported a decrease on this subscale, suggesting a decrease in their awareness levels.

On the PHLMS acceptance subscale, three participants scores increased post-group compared to pre-group, indicating higher acceptance levels, whilst two participants' scores reduced, indicating their acceptance levels had reduced.

Anxiety symptoms

Glasgow Anxiety Scale (GAS-ID). Utilising the GAS-ID test-retest reliability figure of 0.953 and the SD of 10.6 (Mindham and Espie, 2003), the Jacobson and Traux (1991) formula was used to calculate the GAS-ID reliable change criterion. The reliable change criterion was 6.37, indicating participants' GAS-ID scores would need to change by ⩾7 points to demonstrate statistically reliable change. Results therefore indicate two participants (one and four) demonstrated statistically reliable change on their pre and post-group scores. Participant four also showed clinically significant change, due to their pre-group score being above the clinical cut-off (13), and their post-group score being below 13.

The Change Interview. Comments from the change interview relating to anxiety symptoms are outlined in Table 9.

Mindfulness skills

Philadelphia Mindfulness Scale (PHLMS). Due to the PHLMS not being designed and validated for those with ID, internal consistency and standard deviation was calculated based on participants' pre-group scores. Cronbach's alphas for the 10 awareness and 10 acceptance items were 0.797 and 0.907 respectively. Standard deviations were calculated at 5.0 for the awareness subscale and 7.6 for the acceptance subscale. The Jacobson and Traux (1991) formula was then used to calculate the reliable change criterion on each subscale. The reliable change criterion was 6.28 for the awareness subscale and 6.44 for the acceptance subscale, indicating participants' scores would need to change by ⩾7 points on the awareness and acceptance subscales to demonstrate statistically reliable change. Results indicate no participants demonstrated a statistically reliable change between their pre and post-group awareness subscale scores. Participants two and four demonstrated a statistically reliable reduction in their acceptance scores post-group compared to pre-group.

Change Interview. Comments from the change interview relating to mindfulness skills are outlined in Table 9.

Table 9. Quotations from the Change Interview.

Domain	Quotations
Anxiety symptoms	*Like before I used to panic and worry about either my future or any of other plans at home or at day centre. But I feel a big difference between then and now.* – Participant 2 *I think they'd say I'm much calmer.* – Participant 3 *It's all stayed the same* – Participant 4 *I feel fine.* – Participant 5
Mindfulness skills	*Well everything what's in the group [was helpful]. All the, when you put your hands on the table like that. Yeah that were helpful. That were very good.* – Participant 1 *It takes my mind somewhere else.* – Participant 2 *I found the hands one helpful* – Participant 2 *I like the hands on the table and the clouds were the best ones…. Because before, we just learnt to take time out and go to the staff but now I can just do it on my own* – Participant 3
Relating mindfulness and anxiety	*I get stressed very often and I have a lot of issues and thoughts in my head so I can sometimes have outbursts. But having the techniques has helped me to not have the outbursts a lot better.* – Participant 3 *It's helped me because I can go off and if I'm stressed, they will tell me to go as well. To take five minutes out and do one of my exercises.* – Participant 3 *I do it with my hands as well. Sometimes I do it over the weekend as well. Because it's nice and peaceful.* – Participant 5

Table 9. (Continued)

Domain	Quotations
Acceptability of mindfulness exercises	*I liked them all* – participant 1 *I found the hands one helpful* – Participant 2 *I would like more homework* – Participant 2 *When you live on your own because I live on my own, it's got to be the ones [exercises] where you've not got to have someone to read out to you.* – Participant 3 *I would say the activities and the group because they're both good. And how you do the activities is very good*. – Participant 3 *I liked everything* – Participant 4 *If you are on your own, like if you're in a private group. It's like, if you're in a private group on your own, you can think. You can think more. There's nobody about, no noise.* – Participant 5 *I had to have somebody to, one of the staff to help me. She tried to help me with the homework as well*. – Participant 5
Additional benefits identified from being in the group	*Well I don't shout at my brother now like I used to. That were one of the main things, you know. Getting on to my brother.* – Participant 1 *Erm, it was nice to be with a bunch of people.* – participant 2 *The group has [helped], I feel like I can go to someone if I needed help* – participant 2 *Like you know if I needed help, then either you or [facilitator 2] would help me out if I had a problem. And like, I've been off ill and like you did some catch up.* – participant 2 *Erm, it was nice to be with a bunch of people.* – Participant 2 *Because I know them [other group members] it were alright. I thought it would have been a bit strange because you're doing things, it's not like a normal group, you're doing emotional things. But it were fine. Because it's not like a session, it's more a personal session and you're going through personal feelings*. – Participant 3 *Erm, I think it works better in a group. Because you're all working together, plus you've got you and [facilitator 2] and you've got [day centre staff] so you all work together*. – Participant 3 *I would have liked it to have been longer" [more sessions]* – Participant 3 *Nice to be in a group with different people in as well. Different people. I like that because there were different people.* – Participant 5

Relationship between mindfulness skills and anxiety levels

Correlating PHMLS and GAS-ID scores. The relationship between perceived change in anxiety levels (measured by GAS-ID) and perceived change in acceptance (measured by PHLMS), and the relationship between perceived change in anxiety levels (measured by GAS-ID) and perceived change in awareness (measured by PHLMS) was investigated using Pearson product-moment correlation coefficient. Preliminary analyses revealed no violation of the assumptions of normality, linearity and homoscedasticity.

There was a strong, negative correlation between change in anxiety and change in acceptance, r= -.851, n= 5, p= .068, with greater reductions in anxiety associated with greater increases in awareness.

No correlation was found between change in anxiety and change in awareness, r= .015, n= 5, p= .980.

The change interview. Comments from the change interview relating to the relationship between mindfulness skills and anxiety levels are outlined in Table 9.

Additional benefits

Comments from the change interview indicated that participants identified additional benefits from being in the group. Comments are in Table 9.

Feasibility

Resources. Twelve staff hours were used for preparation (reading, finding and preparing resources, planning sessions), 12 hours delivering sessions and six hours administering outcome measures.

Rooms at the day-centre were easily bookable, however the same room was not available for every session.

Participant engagement. Four participants attended all sessions, with one participant missing session three due to illness. One of the original six participants withdrew

from the group due to a family bereavement at session three, leaving five participants whose data was used.

All participants actively engaged in the sessions; however assistance was required from day-centre staff, particularly during written activities (e.g. the mindfulness log). A comment in the change interview indicated that one participant had a desire for sessions to continue ("*I would have liked it to have been longer" [more sessions]* – Participant 3).

Acceptability of outcome measures. All participants completed each item of the GAS-ID and PHLMS. However, it was observed that when completing the PHLMS, participants found the content of the questions difficult to understand, despite adaptations being made.

Adherence to session plan/intervention. The mindfulness content planned for each session was adhered to.

Facilitator competence ratings are given in Table 10. Definitions of each competence can be found in Chawla et al. (2010). Each facilitator was scored from 1 (low competence) to 5 (high competence).

Table 10. Facilitator competence ratings

	Inquiry		Attitude		Key questions		Expectations	
Session	F1	F2	F1	F2	F1	F2	F1	F2
1	3	3	4	4	1	1	1	1
2	5	5	4	4	3	3	3	3
3	5	5	5	5	3	3	4	4
4	5	5	4	4	4	4	4	4
5	5	5	5	5	4	4	4	4
6	5	5	5	5	4	4	4	4

* F1 = Facilitator 1, F2 = Facilitator 2

Participants also rated elements of each session on a scale of 1 to 3 (with 1 indicating a negative response, 2 indicating average, and 3 indicating a positive

response). The mean scores for each question in each of the six sessions are displayed in Table 11 and were consistently high for each session.

Acceptability of mindfulness exercises. Participants engaged well with the mindfulness exercises. Comments from the change interview regarding the exercises are outlined in Table 9.

Table 11. Mean scores on the session rating scale.

Session	1. How was the session?	2. Are we working well as a team?	3. Did you understand today's session?	4. How did you find the exercises?
1	2.85	3	3	2.85
2	3	3	3	3
3	2.8	2.8	2.8	3
4	3	3	3	3
5	2.83	2.83	2.83	2.83
6	2.83	2.83	2.83	2.83

Discussion

Results are discussed with regards to the evaluation aims and previous literature below. Limitations, future research and clinical implications are also discussed.

Aims

1. Is teaching mindfulness skills in a group setting (a mindfulness-based group intervention) effective at reducing self-reported symptoms of anxiety in those with ID?

Results on the GAS-ID suggest that four participants' anxiety reduced having attended the group; two of these participants demonstrated a statistically reliable change, with one achieving a clinically significant change. This suggests that,

statistically, teaching mindfulness skills in the group was effective at reducing self-reported anxiety for two participants. This finding moves beyond previous findings which demonstrated reduced anxiety by using mindfulness as part of a wider therapeutic approach (Idusohan-Moizer et al., 2015). However, as not all participants benefitted, some participants may have benefitted from a wider therapeutic approach.

Comments in the change interview suggest that participants who did not achieve a statistically reliable reduction on the GAS-ID still reported anxiety-related benefits to being in the group (e.g. "*before I used to panic and worry"* and "*I think they'd say I'm much calmer"*). These findings are similar to that of Yildiran and Holt (2015), but also suggest that participants still report benefits having used mindfulness without relaxation.

Other benefits were also reported in the change interview, such as better relationships. Considering that mindfulness can reduce emotional reactivity (Haydicky, 2010), it might be suggested that should one not immediately act on their difficult emotions due to being better equipped with mindfulness techniques, their relationships with others may improve as a result.

2. a) Do participants report an increase in mindfulness skills having attended the group?

Only one participant reported an increase in their awareness on the PHLMS post-group, with the remaining participants reporting a decrease, but none of these changes were statistically reliable. Three participants reported an increase in their acceptance skills on the PHLMS post-group (not statistically reliable), whilst two reported a reduction which was statistically reliable. This suggests that some participants' acceptance skills worsened since attending the group.

It is unclear how attending the group may have led to a decrease in acceptance skills for two participants. Had this been due to group design or delivery, one might expect a reduction for all participants. Participants did not report a reduction in mindfulness skills in the change interview. Therefore, the scores on the PHLMS may be explained by the measure not being designed for those with ID. Participants found it difficult to understand the items even with prompts and were

unable to define what the questions meant when asked. Therefore, it is suggested that PHLMS scores for all participants may not be a true reflection of participants' mindfulness skills, and further strengthens the need for development of a mindfulness measure for those with ID.

Change interview information indicated that some participants used mindfulness skills outside of the session, suggesting an increase in mindfulness skills. One participant indicated that the exercises "*takes my mind somewhere else*". This comment is in line Brown and Ryan (2003) who suggest that using mindfulness is in contrast to habitual or automatic functioning that individuals often engage in.

Therefore, whilst no statistically reliable increase in mindfulness was found for any participant, this may be due to a weakness in the measure used, with qualitative information at odds with PHLMS scores.

2. b) Is the active ingredient of the group (mindfulness) related to the targeted outcome (reduced anxiety) of the group?

Whilst no statistical relationship was found between change in anxiety and change in acceptance, correlational analysis found greater reductions in anxiety were associated with greater increases in awareness. However, it is argued that these results cannot be relied upon due to questionable reliability of PHLMS scores, and due to the correlations not reaching statistical significance, which may be explained by wide confidence intervals in such a small sample.

Qualitative information from the change interview suggests that some participants related using mindfulness activities with reduced anxiety. The benefits that participants identified (e.g. not having outbursts, reducing stress) indicated that they were experiencing reduced emotional reactivity and stress reduction, benefits which are consistent with being mindful in the moment (Davis and Hayes, 2011).

Interestingly, the participant who achieved a clinically reliable reduction in anxiety also achieved a statistically reliable reduction in their acceptance skills. The reduction in mindfulness skills is at odds with what would be expected and may suggest other change processes occurring (i.e. being part of a group) or may further strengthen the argument that their PHLMS scores were unreliable.

3. Is it feasible for this group to be implemented as a regular offering from the CLDT service?

Less preparation time than the current 12 hours would be required in future due to resources having already been sourced and adapted. Additionally, the six hours used for outcome measures could be reduced by asking support staff at the day-centre to administer these.

Delivery of the sessions took 12 NHS staff hours. Individual sessions would have used approximately 30 hours, suggesting that the group is a more efficient use of staff time, which may serve to streamline resources and reduce CLDT psychology waiting times.

Participant engagement was high, as reflected in the attendance figures. Attrition was minimal, with one person leaving the group due to external circumstances. This, along with the desire for more sessions, suggests that those with ID are likely to engage in any future groups.

The inclusion of two day-centre staff in the session was vital for participant assistance, particularly written and homework tasks. Requiring staff assistance was mentioned by participants in the change interview. The inclusion of support staff should therefore continue if the group is delivered again.

Adherence to each session plan was excellent, suggesting that the content can be delivered within the session timeframe. Competence of the facilitators in mindfulness skills was session dependent. Facilitators scored lower in session one, but this served as a group induction rather than teaching mindfulness skills. In future, it may be prudent for mindfulness skills to be introduced earlier to maximise learning. Participants rated each session highly in terms of content, understanding and how the facilitators worked together.

Participants found the more experiential exercises (e.g. soles of the feet) most helpful and indicated they used these the most. This is consistent with the literature suggesting mindfulness is a successful intervention for those with ID due to the experiential nature of the exercises (Brown and Hooper, 2009). Therefore, it may be beneficial to increase the amount of experiential exercises in future.

Limitations and future research

To reduce demand characteristics or socially desirable answers, and to build on weaknesses in previous studies (Yildiran and Holt, 2015) it was hoped that day-centre staff would administer the pre and post-group measures. However, due to staffing numbers, the facilitators administered these measures, and this could have led to socially desirable answers.

Due to the researcher's placement coming to an end, administration of follow-up measures was not possible. Any long-term effects of attending the group are therefore unknown and it is suggested that follow-up measures (e.g. three months later) are administered in any future group.

The PHLMS was an unsuitable measure of mindfulness for those with ID which may have impacted on participants' responses. This impacted on the ability to address the research aim as to whether mindfulness skills had increased. This research gap should be addressed by a mindfulness measure being developed for those with ID, which would allow for a more accurate measurement of mindfulness skills, thereby better informing any future service evaluations.

Although mindfulness was the intervention, rival possibilities of change in anxiety should also be considered. Three participants indicated that just being part of the group and being supported by the group was beneficial. This may be an area for further research.

Statistically reliable reduction in anxiety not being achieved for every participant may be explained by individual differences such as cognitive ability. For example, one participant indicated that the noise in the group interfered with cognition. This is a weakness of delivering a group provision over one-to-one provision which can be more individually tailored and formulation led.

Clinical implications and conclusion

In conclusion, whilst four participants reported a reduced anxiety on the GAS-ID having attended the group, statistically reliable changes were achieved for two participants. However, those who did not achieve statistically reliable changes still qualitatively reported less anxiety having attended the group. There were also other

positive changes reported, such as improvements in relationships. As the group delivered solely mindfulness interventions and participants still reported positive outcomes, it moves beyond previous studies which have combined mindfulness with other interventions (Idusohan-Moizer et al., 2015; Yildiran and Holt, 2015) and suggests that mindfulness alone can lead to benefits. It also considers the effectiveness of standalone mindfulness in a clinical population, with previous studies focusing on non-clinical populations (Blanck et al., 2018).

The only statistically reliable change on the PHLMS was for the participants who reported a decrease in acceptance skills. Nonetheless, in the change interview some participants did report a positive change in their mindfulness levels which contradicts their scores on the PHLMS. It may be that the PHLMS was not an appropriate measure for capturing change in those with ID due to its complexity, although no ID specific measure has been developed. Statistically, a relationship was found between the active ingredient of the group (mindfulness, specifically awareness) and the targeted outcome (reduced anxiety). However, this cannot be relied upon due to questionable reliability of PHLMS scores, and the small sample size meaning significance was not reached. Qualitative information in the change interview indicated that participants were linking increased levels of mindfulness with reduced anxiety. However, rival possibilities of change were also mentioned, such as being part of a group and feeling supported.

It would be feasible to deliver this group again as it had some positive benefits, high participant engagement, acceptability of mindfulness exercises, good adherence to the session plan and is more resource efficient. However, mindfulness might be incorporated earlier, with more experiential exercises. Support staff should continue to be utilised in future groups. To increase understanding of the effectiveness of the group at reducing anxiety and increasing mindfulness, any future groups should continue to be evaluated for the targeted outcomes, with evaluation being enhanced once a more acceptable mindfulness measure is available for those with ID.

Overall, continued provision of this group could streamline resources and reduce CLDT psychology waiting times. Although not all to a statistically reliable level, most participants reported reduced anxiety symptoms, and participants identified being able to use their mindfulness skills outside of the group to help with

their anxiety, suggesting self-management. Continuing to offer the group to those with ID will also contribute towards ensuring equality of access to mental health care for this population.

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