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A typology of modifications to peer support work for adults with mental health problems

Charles, A; Thompson, Dean; Nixdorf, R ; Ryan, G; Shamba, D ; Kalha, J ; Moran, G ; Hiltensperger, R ; Mahlke, C ; Puschner, B ; Repper, J; Slade, M; Mpango, R

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Title: A typology of modifications to peer support work for adults with mental health problems: systematic review

Short Title: Modifications to mental health peer support

A Charles[a]
D Thompson[a]
R Nixdorf
G Ryan
D Shamba
J Kalha
G Moran
R Hiltensperger
C Mahlke
B Puschner
J Repper
M Slade [b]
R Mpango[b]

Abstract

Background

Peer support work (PSW) roles are being implemented internationally, and increasingly in lower-resource settings. However, there is no framework to inform what types of modifications are needed to address local contextual and cultural aspects.

Aims

To conduct a systematic review identifying a typology of modifications to peer support work for adults with mental health problems.

Method

We systematically reviewed the peer support literature following PRISMA guidelines for Systematic reviews. All study designs were eligible and studies were selected according to the stated eligibility criteria and analysed with standardised critical appraisal tools. A narrative synthesis was conducted to identify types of, and rationales for modifications. PROSPERO: CRD42018094832.

Results

A total of 15,300 unique studies were identified, from which 39 studies were included with only one from a low-resource setting. Six types of modifications were identified: role expectations; initial training; type of contact; role extension; workplace support for peer support workers; and recruitment. Five rationales for modifications were identified: to provide best possible peer support; to best meet service user needs; to meet organisational needs, to maximise role clarity; and to address socio-economic issues.

Conclusion

PSW is modified in both pre- and un-planned ways when implemented. Considering each identified modification as a candidate change will lead to a more systematic consideration of whether and how to modify peer support in different settings. Future evaluative research of modifiable versus non-modifiable components of PSW is needed to understand the modifications needed for implementation among different mental health systems and cultural settings.

Key words

Peer support, mental health, implementation, systematic review

Introduction

Recovery is an approach that focuses on supporting people with mental health conditions to live as well as possible (1), whether or not symptoms remain (2). Recovery-orientation has emerged as a global mental health priority e.g. in the World Health Organization Mental Health Action Plan 2013-2020 (3), and is national mental health policy in many countries e.g. UK (4). Peer support workers (PSWs) are a visible manifestation of a recovery-orientation (5, 6) involving people with lived experience of mental health problems helping others to recover from mental health conditions. PSW roles are being implemented internationally, and increasingly in lower-resource settings as a cost-effective approach to reduce the burden of mental health problems (7, 8), to address the mental health care gap (9, 10), and as a form of 'task-sharing' (9) to help support the service delivery of already strained and overwhelmed mental health systems. Overall, peer support has been identified as a central approach to recovery (11), and is endorsed by psychiatrists (12).

Some systematic reviews identify the limited evidence base relating to PSWs (13), but overall the weight of evidence indicates positive outcomes including empowerment (14), hope (15, 16), social relationships (17, 18), self-efficacy (19), recovery (20), symptomatology (21) and reduced readmissions to acute care (22). PSWs are an increasingly common member of the multi-disciplinary clinical team, interacting with other professionals yet being asked to retain a 'lived experience' identity. For mental health professionals, this can create dilemmas in terms of relationships, issues of confidentiality, ethics, decision-making, and role clarity (23). In order to work effectively with PSWs, a clear understanding of the role and how it is modified in different clinical populations and settings is needed. The aim of this review was to characterise pre-planned (modifications that were planned or allowed for in the design of the intervention arising from decisions made before implementation) and un-planned (modifications made due to unforeseen changes to the intervention that occur after implementation) modifications to mental health peer support work for adults with mental health problems. The objectives were to develop a typology of types of modifications, to characterise the rationales for these modifications, and to identify modifications made specifically in low- and middle-income settings.

Method

The protocol of this systematic review was developed in accordance with PRISMA guidelines (24) and registered on PROSPERO (International Prospective Register of Systematic Reviews) on 24 July 2018: CRD42018094832.

Eligibility criteria

We included studies about PSWs supporting adults aged 18 years or older with a primary diagnosis of mental illness, and those which explicitly identified modifications including changes, variations, or adaptions made before ('preplanned') or whilst ('unplanned') implementing a peer support worker intervention. A modification could be identified in various ways, such as changes to the intervention manual or to the role of the PSW, and an inclusive approach to inclusion was used. We excluded studies that: did not explicitly refer to modifications; had fewer than 3 participants; and studies that reported on mutual aid, peer-run organisations, naturally occurring peer support, peer navigation interventions and peer support delivered exclusively online. No studies were excluded on the basis of comparators, control conditions, service setting or clinical diagnosis. Included study designs were randomised controlled trials, controlled before and after studies, cohort studies, case-control studies and qualitative studies. Studies were included if reported in English, French, German, Hebrew, Luganda, Spanish or Swahili (chosen as languages in UPSIDES Study sites), with a date of publication on or before July 2018.

Information sources

Six data sources were used: (1) electronic bibliographic databases (n=9) searched were MEDLINE (OVID), EMBASE (OVID), Cumulative Index of Nursing and Allied Health Literature (CINAHL) (EBSCHO) PsycINFO (OVID) Scopus, Web of Science, Google Scholar, OpenGrey, ProQuest Dissertations & Theses A&I, African Journals OnLine (AJOL), and Scientific Electronic Library Online (SciELO); (2) table of contents (n=9) of *International Journal of Social Psychiatry*, *Social Psychiatry and Epidemiology*, *Psychiatric Services*, *Journal of Recovery in Mental Health, Journal of Mental Health*, *Journal of Mental Health Training*, *Education and Practice*, *Psychiatric Rehabilitation Journal*, and *BJPsych International* (chosen as publishers of PSW studies); (3) conference proceedings of European for Mental Health Service Evaluation (ENMESH) (n=12 conferences since 1994) and

Refocus on Recovery (n=4 conference since 2010) (chosen as recovery-relevant academic conferences with available proceedings); (4) websites (n=10): peersforprogress.org; together-uk.org; mentalhealth.org.uk; mind.org; mihinnovation.net; inaops.org; peerzone.info; cpr.by.edu; peersupportcanada.ca; medicine.yale.edu/psychiatry/prch (chosen as they host PSW materials) (5) a preliminary list of included studies was sent to experts (n=36) requesting additional eligible studies; (6) forward citation tracking was performed on all included studies using Scopus and backward citation tracking by hand-searching reference lists of included studies.

Search strategy

The search strategy was adapted from a published systematic review concerning peer support for people based in statutory mental health services (25). The search strategy was modified for each database, and an example of the search strategy used for MEDLINE is shown in Online Supplement 1. All searches were conducted from database inception until July 2018.

Study selection

After removing duplicates, the titles and abstracts of all identified citations were screened for relevance against the inclusion criteria by DT, with a randomly-selected 5% sample independently assessed by RN. Concordance between the two reviewers was 91%. Full texts were single-screened by DT. DT and RN then independently extracted data from 55% of included publications, so a randomly-selected 10% were independently extracted by both researchers, who discussed their data extraction to check for adequate agreement.

Data abstraction

For each included publication, information was extracted on (1) study characteristics including study design, study participant inclusion and exclusion criteria, and sample size; (2) mode of intervention delivery; (3) where the intervention was performed including country, and service setting; and (4) pre-planned and un-planned modifications made to the peer support work, and the rationale for planned and un-planned modifications. The data abstraction table is shown in Online Supplement 2.

Quality assessment

The Critical Appraisal Skills Programme (CASP) was used to assess the quality of eligible studies. CASP checklists do not provide an overall scoring, so a scoring system used in a previous systematic review (26) was applied. Each CASP item rated 'Yes' scored 1 point and each item rated 'No' scored 0 points. The percentage score for the 10-item CASP randomized controlled trial checklist, the 10-item CASP qualitative checklist, the 12-item CASP cohort checklist and the 11-item CASP case control checklist was calculated, with studies scoring ≥60% graded as good quality, studies scoring 45% to 59% graded as fair quality, and studies scoring below 45% graded as poor (27, 28).

Synthesis of results

A three-stage narrative synthesis was conducted on included papers (29), modified in line with recent reviews (30, 31). The four analysts (AC, RN, MS, DT) came from varied professional (nursing, psychology) and disciplinary (health services research, social science, psychotherapy) backgrounds. In Stage 1 (Developing a preliminary synthesis), modifications and rationales for modifications identified in included studies were synthesised. Findings were tabulated and an initial coding framework was developed through thematic analysis to group modifications which were pre-planned and un-planned, and rationales for both types of modification. Vote counting of number of papers identifying each theme was performed, the data was interpreted as providing an initial indication of strength and ordering of themes. This method could have been interpreted as providing an indication of themes more amenable to change rather than strength, however for the purpose of this paper vote counting was used to determine the strength of themes. A preliminary draft of the modifications and rationale for modifications was developed and refined by analysts. In Stage 2 (Comparison between studies), the relationships within and between studies were explored. Identified modifications and rationales were compared between higher-income versus lower-income countries and pre-planned versus un-planned modifications. In Stage 3 (Assessing the robustness of the synthesis), the findings from sub-group analysis of only good quality studies was compared with the framework from all included studies.

Results

Included studies

The search identified 15,300 studies, from which 39 were included. The flow diagram is shown in Figure 1 and the complete data abstraction table including all references is shown in Online Supplement 2.

Insert Figure 1 here

The 39 included studies were predominantly conducted in higher-income countries, comprising USA (n=26), UK (n=5), Canada (n=4), Australia and USA (n=1), Australia (n=1), England (n=1) and Republic of Ireland (n=1), with a single study conducted in an upper-middle income country (Libya). Designs comprised qualitative (n=12), randomised controlled trial (n=13), pre-post (n=10), case control (n=3) and cohort (n=1).

Stage 1 (Developing a preliminary synthesis)

Six types of modifications to peer support work were identified, as shown in Table 1. The coded text including detailed examples from included publications is shown in Online Supplement 3.

Insert Table 1 here

Five types of rationale for modifications to peer support work were identified, as shown in Table 2. The coded text including detailed examples from included publications is shown in Online supplement 4.

Insert Table 2 here

Stage 2 (Comparison between studies)

Overall, 22 (56%) of 39 included studies reported only pre-planned modifications, 10 (26%) reported only un-planned modifications, and 7 (18%) studies reported both pre-planned and un-planned modifications. Including only the 22 studies reporting pre-planned instances of modifications did not lead to deletion of any of the strongest themes. However, the ordering changed, with the four

strongest themes being Role expectations, Type of contact, Role extension, and Workplace support for PSWs. Including only the ten studies reporting un-planned modifications in the framework did not markedly change the ordering, with the three strongest themes being Role expectations, Initial training and Role extension. Across all included studies, 38 (97.4%) were conducted in high-income countries and 1 (2.6%) in a low-middle income country. Including only the 38 studies conducted in high-income countries did not change the strength or ordering of themes. Including the one study conducted in a low-middle income country led to the deletion of four themes: Type of contact, Role extension, Workplace support for PSWs and Initial recruitment. The two strongest themes in the low-middle income study setting were Role expectations and Initial training, with the sub-themes of 'materials used with service users', 'structure', and 'topics covered'.

A total of 36 (92%) of the 39 included studies reported a rationale for modifications, comprising 22 (61.1%) providing rationales for planned modifications, 9 (25%) for un-planned modifications, and 5 (13.8%) studies reporting rationales for both pre-planned and un-planned modifications. Including only the 22 studies reporting rationales for planned modifications in the framework did not lead to any changes to the ordering or deletion of any themes, with the three strongest themes being, To provide best possible peer support, To best meet service user needs and, To meet organisational needs. Including only the nine studies reporting rationales for un-planned modifications, the ordering changed slightly, with To provide best possible peer support, To meet organisational needs and To maximise role clarity emerging as the strongest themes. A total of 35 (97.2%) studies were conducted in high-income countries and 1 (2.8%) in a low- or middle-income country. Including only the 35 studies conducted in high-income countries did not change the order or strength of themes in the rationale framework. Including the one study conducted in a low-middle income country led to the deletion of three themes: To best meet service user needs, To maximise role clarity and To address socio-economic issues. The strongest themes were To provide best possible peer support and To meet organisational needs. The sub-themes included: 'to match on cultural aspects', 'to enhance service use of self-management strategies when not with PSW', 'to meet organisational resources' and 'to meet infrastructure of care'.

Stage 3 (Assessing for the robustness of synthesis)

The quality rating of studies is shown in Online Supplement 5. Studies were rated as good quality (n=28), fair quality (n=5) or poor quality (n=6). Excluding the 11 studies rated as poor or fair quality did not greatly influence the content and strength-of-theme ordering for either modifications or rationales. The three strongest modification themes remained Role expectations, Initial training and Type of contact, with only Workplace support for PSWs moving up in the order to joint third strongest theme. The order and strength of themes did not change markedly in the rationale framework, with To provide best possible peer support, To meet organisational needs and To best meet service user needs being the strongest themes.

Discussion

This systematic review and narrative synthesis identified a typology of five rationales and six types of modifications to formal mental health peer support work when implemented in diverse settings. Insufficient evidence was available to identify types or rationales of modifications specific to lower-resource settings. There was no evidence of study quality impacting on the findings, and most types of modification occurred both as planned and un-planned modifications.

Peer support is a complex intervention. Formal reporting of the intervention would support understanding of modifications. The TIDieR reporting guidelines identify how to report complex interventions to allow reliable implementation and replication (32). Item 10 of the TIDieR checklist is 'Modification: If the intervention was modified during the course of the study, describe the changes (what, why, when and how)' – changes which in this review were called un-planned modifications. Earlier TIDieR items involve a complete description of the intervention, covering what in this review was called planned modifications. As none of the included studies used the TIDieR reporting guidelines, descriptions of modifications and their rationale were inconsistent, so under-reporting of modifications is probable which would lead to not all relevant PSW studies with modifications being included.

No study was designed to anticipate un-planned modifications. In trial methodology, an adaptive trial design involves pre-planned modification of trial procedures based on interim analysis during the conduct of the trial (33). This design is an approach to reducing resource use, decreasing time to trial

completion and improving the likelihood that trial results will be scientifically or clinically relevant (34). A key feature of adaptive designs is that modifications are expected, and based on continuous learning as data accumulates during the trial. None of the included studies used an adaptive design, even though this is a relevant approach. For example, adaptive enrichment occurs when interim analysis shows that a treatment has more promising results in one subgroup of patients, in which case the eligibility criteria are modified to investigate the efficacy of the intervention in that subgroup (35). The identified un-planned adaptation of modifications to the target group could be more effectively managed by adopting an adaptive enrichment strategy.

The highest proportion of un-planned to pre-planned modifications occurred for the Initial training modification. PSW training programmes have developed internationally in an uncoordinated way, including both accredited and non-accredited courses. Networks are emerging such as the International Association of Peer Specialists (www.inaops.org) and the Global Network of Peer Support (www.peersforprogress.org), but as yet there are no widely agreed consensus statements on the key non-modifiable and modifiable components of PSW initial training. Established approaches to differentiating between what can and cannot be modified could be followed (36).

Strengths and limitations

The strengths of this review include the multi-language and systematic strategy used, and the robustness of methodology including multiple analysts and quality appraisal of studies. Several limitations of this review can be identified. First, the quality rating tool used in the synthesis excluded few studies, and resulted in minimal changes to the ordering of themes. Other critical appraisal tools could also be considered or used in combination with CASP in future studies to enhance robustness of evaluation. Second, the absence of established peer support brands made provenance and modifications difficult to establish, as has been found with other complex interventions (37). Developing named manualised approaches to implementing peer support would make it easier to identify when future studies are replicating versus adapting the approach. Third, meaningful comparisons between modifications made in higher versus lower income settings was not possible because only one non-high income setting study was included. In addition, studies conducted in different global jurisdictions including the global south were not located or included. More searching of

grey literature, modifications to the inclusion criteria and a broader expert consultation might have identified studies from lower-income settings and a wider range of countries, e.g. China (38) and Uganda (39), or related studies such as the ReDeAmericas Program in Latin America (www.cugmhp.org/research/redeamericas).

Implications

The review provides an evidence-based framework for systematic consideration of different types of candidate modification to peer support implementation. An appropriate approach would involve considering each rationale in turn, framed as a question, for example ‘What needs to be modified to provide best possible peer support in our setting?’ Where this process suggests that modification may be indicated, the modification types identified in relation to the rationale provide candidate changes to consider in relation to each question. This approach is likely to lead to a more systematic consideration of whether and how to modify the approach to peer support to different settings, especially when informed by an understanding of influences on implementation (40).

Identifying the wide range of modifications also has research implications. Evaluative research to identify the non-modifiable versus modifiable components is needed, to differentiate between desirable local adaptations versus non-desirable changes to the core components of peer support. Evaluations of peer support implementation identify that differing organisational cultures lead to differences in role expectations (40), and issues of professionalism and practice boundaries are common (41). Identifying when a modification is sufficiently large as to mean it is no longer a peer support role is an important future research focus. A second research priority is understanding when and where modifications are needed for implementation of peer support work, such as in work with asylum seekers and refugees (42), and work in different types of clinical settings and populations. For example, service setting of hospital versus community and clinical population may be a focus for future research. The UPSIDES Study is addressing the challenge of investigating how peer support work can be implemented in settings which differ in income levels, through implementation research and a randomised controlled trial in sites in Ulm (Germany), Hamburg (Germany), Kampala (Uganda), Dar es Salaam (Tanzania), Beer Sheva (Israel) and Pune (India). As interest in peer support work is

growing internationally, evidence-based approaches to modifying the PSW role to meet local needs whilst retaining role integrity become essential.

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Conflicts of Interest

The authors declare that they have no conflict of interest.

Ethical Standards

The manuscript does not contain clinical studies or patient data.

Availability of Data and Materials

All collected data are included as online supplements.

A. Charles. MSc, School of Health Sciences, Institute of Mental Health, University of Nottingham, UK. **D. Thompson**, PhD, Institute of Applied Health Research, University of Birmingham, UK. **R. Nixdorf**, MSc, Research Assistant, Universitätsklinikum Hamburg-Eppendorf, Germany (Department of Psychiatry). **G. Ryan,** MSc, London School of Hygiene and Tropical Medicine, UK. **D. Shamba**, MSc, Ifakara Health Institute, Tanzania. **J. Kalha**, MSc, Centre for Mental Health Law and Policy, Indian Law Society, Pune, India. **G. Moran**, PhD, Ben Gurion University of the Negev, Beer Sheva, Israel. **R. Hiltensperger**, MSc, Department of Psychiatry II, Ulm University, Ulm, Germany. **C Mahlke**, PhD, Universitätsklinikum Hamburg-Eppendorf, Germany (Department of Psychiatry). **B. Puschner**, PhD, Department of Psychiatry II, Ulm University, Ulm, Germany. **J. Repper**, PhD, Nottinghamshire Healthcare NHS Foundation Trust, UK. **M. Slade**, PhD, School of Health Sciences, Institute of Mental Health, University of Nottingham. **R. Mpango**, PhD, Butabika National Referral Hospital, Uganda.

[a] Charles and Thompson are joint first authors
[b] Slade and Mpango are joint last authors

Author for correspondence. Ashleigh Charles, Institute of Mental Health, University of Nottingham, Innovation Park, Jubilee Campus, Triumph Road, Nottingham, NG7 2TU, UK; E-mail: Ashleigh.Charles@nottingham.ac.uk

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Table 1. Types of modifications made to peer support work

#	Modification name	Description of modification	Sub-theme	Number of papers reporting pre-planned instances	Number of papers reporting un-planned instances	Total number of papers reporting this type of modification
1	Role expectations (i.e. what the PSW is employed to do and what are the performance expectations on them?)	Remit of the PSW role	1.1 Target group to work with (i.e. who PSWs work with)	0	2	31
			1.2 Content of PSW (i.e. what PSWs actually do, and what tools do they use?)	6	5	
			1.3 Process of support (i.e. how do PSWs provide support?)	3	5	
			1.4 Structure of support (how PSW is structured and delivered)	1	3	
			1.5 Materials used with service users (how materials are modified)	4	2	
2	Initial training	Training for PSWs before taking on the role	2.1 Structure	2	5	15
			2.2 Topics covered	1	3	
			2.3 Training process	0	4	
3	Type of contact	How PSWs work with service users	3.1 Individual	3	3	13
			3.2 Group	3	0	
			3.3 Individual and group	1	0	
			3.4 Telephone	1	1	
			3.5 Online	1	0	
4	Role extension	Flexibility beyond traditional PSW role	4.1 PSWs develop extra skills or roles	3	2	9
			4.2 PSWs co-work with clinicians	2	2	
5	Workplace support for PSWs	Type of workplace support	5. Workplace support	4	4	8
6	Recruitment	Recruitment to PSW roles	6. Recruitment	1	2	3

Table 2. Types of rationales for modifications made to peer support work

#	Type of rationale	Number of papers reporting this type of rationale	Sub-theme	Number of papers reporting rationales for pre-planned modifications	Number of papers reporting rationales for un-planned modifications
1	To provide best possible peer support	30	1.1 To match on cultural aspects	3	3
			1.2 To increase service user engagement in direct work with PSW	10	2
			1.3 To provide person centred care	4	4
			1.4 To enhance service user use of self-management strategies when not with PSW	3	1
2	To best meet service user needs	16	2.1 To meet physical health needs	4	0
			2.2 To meet mental health needs	5	0
			2.3 To address risk of service user (i.e. risk of relapse or readmission)	1	1
			2.4 To not over-burden service users (i.e. support is tailored to meet learning needs, relevance for clinical population, and to increase engagement)	2	3
3	To meet organisational needs	12	3.1 To reflect organisational resources	1	3
			3.2 To reflect existing infrastructure of care	2	2
			3.3 To meet policy and legislation requirements	2	1
			3.4 To meet technological requirements	1	0
4	To maximise role clarity	7	4.1 To increase role clarity	2	2
			4.2 To better use lived experience in PSW role	0	2
			4.3 To increase PSW motivation and work skills	0	1
5	To address socio-economic issues	4	5.1 To address socio-economic issues of service users	2	1
			5.2 To address socio-economic issues of PSWs	0	1

Figure 1. Flow diagram of the study selection process