

BMJ Open Peer support needs, preferences and experiences of adults with acquired neurological disability: a scoping review protocol

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ABSTRACT

Introduction Peer support is a promising adjunct to traditional rehabilitation methods for helping adults with acquired neurological disability adjust to and navigate life with a disability. However, there is limited guidance on how to implement peer support for this cohort. To help inform peer support practices, the aim of this scoping review is to determine what is currently known about the peer support needs, preferences and experiences of adults with acquired neurological disability.

Methods and analysis The scoping review will be conducted according to guidelines published by Arksey and O'Malley, Levac *et al* and Peters *et al*. Reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews. Systematic searches on five electronic databases (CINAHL, Embase, MEDLINE, PsycINFO and Scopus) will be conducted to identify peer-reviewed research published since 2013 that investigates any type of peer support for adults (18–65 years) with any acquired neurological disability. Information about the study, participant and peer support characteristics, as well as data pertaining to the key outcomes of interest (ie, needs, preferences and experiences), will be charted, summarised and reported. Qualitative data will be analysed using thematic synthesis, and findings will be discussed with 4–6 people with lived experience of acquired neurological disability.

Ethics and dissemination The review does not require an ethics application. It is anticipated that findings will be disseminated through journal publications and conference presentations. Translation of the findings to non-academic audiences will be informed by the consultation with lived experience experts.

INTRODUCTION

Acquiring a neurological disability due to a neurological injury (eg, acquired brain injury, traumatic brain injury) or condition (eg, multiple sclerosis, Parkinson's disease) can have significant and multifaceted impacts on a person's life. Individuals often face a range of cognitive and physical impairments, including difficulties with mobility, sensory functioning, fatigue and information processing.^{1 2} These changes in functioning

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The review will include a range of disability and peer support types to allow a comprehensive overview and nuanced understanding of the evidence pertaining to individuals' needs, preferences and experiences.
- ⇒ Consultation with a research librarian facilitated the development of a robust search strategy and consultation with people with lived experience of neurological disability will strengthen the evaluation of the literature.
- ⇒ The review will follow well-established guidelines for scoping reviews to ensure a rigorous methodology.
- ⇒ Only research published since 2013 will be included, which may exclude relevant earlier work but will ensure findings are relevant to current disability policy and practices.
- ⇒ Peer programmes not evaluated in the scientific literature may not be captured as grey literature will be excluded; however, it is the authors' intention to include this information in a separate environmental scan.

can give rise to psychosocial ramifications, with difficulties performing premorbid activities and social roles profoundly disrupting a person's sense of identity^{3 4} and relationships with family and friends.^{2 5} This can place individuals at risk of social isolation,⁴ negative mental health outcomes⁶ and reduced community participation.⁷ Adults of working age (ie, 18–65 years) are particularly vulnerable to these impacts, as the onset of disability likely presents a significant and unexpected diversion from their expected life path and goals^{4 8}—a process coined 'biographical disruption'.⁹ Concerningly, the complex sequela of symptoms following an acquired neurological disability is not sufficiently addressed by the traditional neurological rehabilitation system, with a large proportion of individuals reporting unmet clinical, social and emotional needs.^{6 10} The medical focus of the rehabilitation system has

been particularly criticised for overlooking psychosocial needs.³ As such, alternative approaches that complement traditional rehabilitation methods are needed to create a more holistic continuum of care.

One such approach that is gaining increasing interest is peer support. Etymologically, the words ‘peer’ and ‘support’ derive from the Latin words ‘par’ and ‘porto’, which translate to ‘equal’ and ‘to carry’.¹¹ Thus, on its most basic level, peer support can be thought of as interactions between equal individuals that help carry someone’s burden or load. The ‘carrying’ function of peers typically comprises emotional, appraisal and informational aspects.^{11 12} Peers provide emotional support by creating empathetic and non-judgemental spaces for sharing experiences and emotions, and appraisal support by validating and normalising a person’s experiences through discussions and social comparisons.^{4 11–13} Informational support involves the platform peers offer for sharing wisdom and skills as well as encouraging collaborative problem-solving and vicarious learning.^{8 11–14} Together, emotional, appraisal and informational support facilitate ‘true’ understanding, acceptance and hope to an extent that is difficult to receive from other social connections and health professionals who do not have the same lived experience.^{4 8 15} In the context of acquired neurological disability, peer support may play a particularly unique role by helping individuals establish a new sense of self^{4 8} and positive disability identity,¹⁶ thereby ‘repairing’ the biographical disruption often evident among adults with acquired neurological disability.^{4 8} In recognition of the potential benefits of peer support, international organisations like the WHO and the United Nations increasingly acknowledge the critical role of peers in complementing and enhancing professionally delivered healthcare and disability support.^{17–19}

Peer support may be of particular importance within disability support systems that emphasise individualisation and self-direction. Such individualised funding systems are becoming increasingly prevalent, with examples including the National Disability Insurance Scheme in Australia and Personal Health Budgets in the UK, introduced in 2013 and 2009, respectively.^{20 21} Individualised funding systems place people with disability at the centre of decision-making by allowing individuals to tailor support to their needs and preferences.^{22 23} While well intentioned, these systems require individuals to be able to set goals, plan supports and make decisions within often highly complex and bureaucratic policy spaces.^{22 23} This makes access to information and support networks that build the decision-making skills and resilience of people with disability critical.^{22–24} Peers are well positioned to provide this necessary information and support by sharing their experiences of navigating the system, providing tips on effectively using available funding and offering encouragement to advocate for one’s needs.^{25 26} Increasing government interest in funding peer support suggests recognition of these benefits.^{24 27 28} For example, a recent review of the Australian disability support system

proposed that long-term funding for peer support should be made available to all people with disability under so-called ‘foundational supports’.^{24 28} This stands in stark contrast to the seemingly sporadic funding through time-limited grants and one-off payments currently evident in Australia (see examples of the current funding system here^{29 30}). If peer support is to receive greater funding, it is critical that peer support programmes are well designed, implemented and evaluated.

However, a major challenge to the field is a lack of clear conceptualisation of what exactly peer support is and how it should be provided.^{12 31 32} Various definitions and alternative terminologies are often used interchangeably to describe peer support, with some alternative terms including peer mentoring, peer education and peer coaching.³¹ A commonly cited concept analysis defined a peer as someone ‘who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population’ (Dennis,¹¹ p329); however, clarity around what characteristics (eg, disability type, demographics, interests) determine feelings of similarity is lacking.^{15 31 33 34} In contrast, Mead’s definition of peer support emphasises its underlying ‘principles of respect, shared responsibility, and mutual agreement of what is helpful’ (Mead *et al*,³⁵ p135). While Mead contends that peer support relationships should strive to reduce power imbalances,³⁵ some peer programmes exhibit seemingly hierarchical structures that select and train certain peers to ‘deliver’ a peer support intervention.¹² The lack of clear conceptualisation is also evident in uncertainty about the essential elements of peer support, with programmes varying significantly in design across dimensions such as the (1) format (eg, one-to-one and group), (2) structure (eg, organically occurring interactions, formal programme), (3) setting (eg, inpatient, outpatient and community), (4) medium (eg, in-person and remote), (5) timing (eg, length, intensity and time point), (6) organisation (eg, peer-led, in collaboration with professionals) and (7) purpose (eg, education and well-being).^{31 33 36 37}

The lack of clear conceptualisation of peer support prevents the field from achieving its full potential. Evidence regarding the effectiveness of peer support is mixed, with only some studies detecting improvements in outcomes like quality of life, community integration and mental well-being.^{33 36 38} The inconsistent effectiveness of peer support across studies may be due partly to its varied implementation formats³⁷ as well as uncertainty around what outcomes peer support should be expected to achieve.³⁹ In addition, research has revealed instances of unhelpful or harmful peer interactions, such as information from peers being perceived as overwhelming and untrustworthy⁴⁰ and interactions with peers being marked by interpersonal difficulties and conflicts.^{11 41} Interacting with a peer who has more difficulties than oneself can be particularly upsetting and may even increase depressive symptoms by provoking uncertainty regarding the progression of one’s own symptoms.^{40 42} Despite the risks

of poorly designed peer support, stakeholders tend not to justify or explain the decision-making underpinning a programme's implementation form.³⁸ Unsurprisingly, research has been calling for more clarity and best-practice guidelines concerning the design and implementation of peer support.^{12 31}

Given that peer support emphasises the importance of directly involving people with disability in the delivery of healthcare, it seems vital that such guidelines are informed and led by the perspectives of people with disability. More specifically, consideration of the needs, preferences and experiences of people with disability should be at the forefront of peer support programmes. Understanding what motivates people to engage in peer support, with whom, when or how they would like to interact and what facilitates or impedes successful interactions can provide critical guidance on how to provide peer support effectively. To establish a nuanced conceptualisation of peer support and a common reference point in the field, it would be particularly useful to understand how peer support needs, preferences and experiences may vary across neurological conditions. Identifying the variabilities and commonalities of these factors is especially important as peer programmes do not necessarily target a particular neurological condition (eg,⁴³) and, thus, may need to align with the needs and preferences of a range of populations.

While individual studies have documented information such as the preferred characteristics of peers⁴⁴ and structure of peer support¹³, a comprehensive overview of this knowledge across different neurological conditions and peer support types is currently missing. Most literature reviews to date focus on the effectiveness and characteristics of peer support^{14 31 33 36 38 39 42 45 46} rather than individuals' needs, preferences and experiences. Reviews that have alluded to these aspects have limited their scope to a specific disability type (ie, multiple sclerosis⁴⁰; Parkinson's disease⁴¹; spinal cord injury⁴⁷ and acquired brain injury³⁷) and peer support type (ie, online peer support^{40 41}; peer support groups³⁷). It is also noteworthy that several reviews have considered only formalised peer support 'interventions'^{42 47}; however, an understanding of naturally occurring peer interactions is equally critical to build a robust understanding of peer support.

Peer support for people with acquired neurological disability may be enhanced by seeking a fuller understanding of peer interactions, remaining open to a broad definition of what peers might consider valuable support and how this may vary across individuals. As a foundation, this scoping review aims to summarise and map the existing literature for evidence on the needs, preferences and experiences of adults with acquired neurological disability concerning peer support. The information collated is hoped to (1) identify key factors that adults with acquired neurological find important in peer support and that should thus be considered when establishing peer support for this cohort, (2) understand how the identified factors vary across neurological conditions

and peer support types and (3) identify gaps in knowledge to guide future research priorities. The review will include a broad range of peer support, including both formal and informal interactions, as well as a variety of acquired neurological disability types.

METHODS AND ANALYSIS

Scoping review methodology was deemed appropriate to address this study's aim, as it enables researchers to comprehensively map the literature in a research area,⁴⁸ including mapping key factors (ie, needs, preferences and experiences) associated with a given concept (ie, peer support).⁴⁹ The review will follow the scoping review guidelines of Arksey and O'Malley,⁴⁸ Levac *et al*⁵⁰ and Peters *et al*.⁵¹ The review will be conducted in six stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarising and reporting the results and (6) stakeholder consultation. Reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Extension for Scoping Reviews.⁵² It is anticipated that work on the review will commence in May 2024 and conclude in November 2024.

Stage 1: identifying the research question

The main research question guiding this scoping review is: 'What are the needs, preferences and experiences of adults (18–65 years) with acquired neurological disability concerning peer support?'

For the purposes of this review, the constructs 'needs', 'preferences' and 'experiences' cover the following aspects, from the perspectives of people with disability:

- ▶ Motivations for seeking out and engaging in peer support.
- ▶ Wants, needs, likes and dislikes about the what (eg, what aspects or content do people like), the when (eg, when do people want to engage), the who (eg, who people would like to interact with) and the how of peer support (eg, how do people want to interact).
- ▶ Facilitators and barriers to seeking out and engaging in peer support.
- ▶ Outcomes of engaging in peer support, including adverse experiences.

Stage 2: identifying relevant studies (developing the search)

The authors developed a systematic search strategy in consultation with a senior research librarian. To develop the search, a list of potential search terms was collated by conducting preliminary searches on the MEDLINE database that combined the broad term 'disability' with either 'peer' or 'peer support'. While these searches were very broad in scope (eg, they also captured non-neurological disabilities), they helped identify keywords and Medical Subject Headings (MeSH) of relevant articles and assess whether any similar reviews on the topic had already been conducted. Additional search terms were identified through prior knowledge of the literature

and handsearching of the MeSH tree. The resulting list of search terms was refined by iteratively testing the relevancy and yield of the search strategy, and accordingly adjusting, removing or adding terms.

The final search strategy contains keywords and MeSH terms relating to two concepts: the population of interest and peer support. Terms for the population describe the overall concept of neurological disability as well as specific neurological injuries and conditions. Terms for peer support describe variations of the concept by combining the word 'peer' with terms such as 'support', 'mentor' or 'volunteer', as well as describing settings where peer support may occur, such as 'support groups' and 'online forums'. Wildcards and truncation operators are used to capture alternative spellings and endings of words, and the Boolean operators 'OR' and 'AND' are used to combine the search terms. Terms for the key outcomes of interest (ie, needs, preferences and experiences) are not included in the search, given that articles may cover these aspects without including relevant key terms in the title or abstract. The final search strategy for MEDLINE is presented in online supplemental appendix 1. In addition to MEDLINE, the search strategy will be adapted and applied to the following electronic databases: CINAHL, Embase, PsycINFO and Scopus.

To find any relevant studies not captured by the developed search strategy, the reference list of all eligible studies and any relevant review articles will be handsearched. In addition, forward and backward author referencing of key authors will be conducted.

Stage 3: study selection

Participants

To be considered for inclusion, studies need to focus on adults aged 18–65 years with a neurological disability that was acquired due to a neurological injury (eg, acquired brain injury and traumatic brain injury) or condition (eg, multiple sclerosis and Parkinson's Disease).

If a study includes a mix of participants with an acquired neurological disability (ie, the target cohort) and participants with non-eligible disability types, the study will be considered eligible if (1) the sample comprises at least 50% of the target cohort and (2) results relating to the target cohort can be isolated and analysed separately. The same approach will be applied to studies that include the perspectives of people other than the person living with disability, such as close others and support workers. This is to ensure the review findings are grounded in the perspectives of people with acquired neurological disability.

Concept

The concept guiding this review is peer support for adults with acquired neurological disability. Peer support not targeted at the person with a disability (eg, peer support for family members) will not be included. Given the lack of clarity and consistency in how peer support is implemented, the term peer support will be used to capture the

wide-ranging forms of interactions that can occur between peers. No restrictions will be placed on the form of peer support, such as the format, structure, setting, medium, timing, organisation or purpose. This wide selection will enable a comprehensive understanding of the evidence and reveal how needs, preferences and experiences vary. However, in order to be eligible, peer support needs to explicitly form part of a study's aim. For example, studies evaluating programmes where peer support may not be the sole focus (eg, online forums, self-management interventions) will be included only if the authors of the study conceptualised peer support as a component of the programme and if results relating to peer support can be discerned from other aspects of the programme. Moreover, studies need to investigate preferences, needs or experiences concerning peer support from the perspective of adults with acquired neurological disability (eg, in the form of self-report measures or interviews) to be considered for inclusion.

Context

No restrictions will be placed on the context of studies.

Type of sources

Only peer-reviewed research with primary empirical data will be considered for inclusion; grey or unpublished literature, as well as studies without primary data (eg, literature reviews and commentaries), will not be included. It is acknowledged that excluding grey literature will limit the breadth of the scoping review. However, this restriction was placed to avoid overlap with an environmental scan the authors are planning to conduct, which will predominantly rely on grey literature describing and evaluating current peer support programmes.

To be eligible, studies also need to use a quantitative, qualitative or mixed-methods design and be published in or after January 2013. This time frame was chosen in recognition of the significant shifts in the policy landscape^{20 21} as well as increasing acknowledgement of the importance of peer relationships from international organisations (ie, WHO and United Nations)^{17–19} in the early 2000s. By focusing on studies published since 2013, it is hoped the findings will be up to date and relevant to current peer support policies and practices.

In addition, only papers published in English will be included. As mentioned, the concept of peer support and the various terms used to describe peer support are still relatively poorly defined and understood in the English language. Exploring peer support through the lens of other languages would likely introduce further complexity and possibly misinterpretations. Thus, although limiting the scope of the review, the English-language criterion was set for feasibility reasons and to avoid confounding the review findings by cultural and language differences.

Screening process

Identified articles will be uploaded to EndNote V.21⁵³ and Covidence⁵⁴ for screening purposes. Following the

removal of duplicates using Covidence, all authors will individually pilot-test the eligibility criteria with 20 articles and then meet to discuss and amend the criteria where needed. The abstracts and titles of all articles will be independently screened by two reviewers (CW and either JD, DW or MB). Following the initial screening phase, the full text of all remaining articles will be retrieved and again double-screened by CW and either JD, DW or MB to assess eligibility. Reasons for exclusions will be recorded, and the results of the screening process will be presented in a PRISMA flow chart.⁵⁵ The reviewers will meet regularly throughout the screening process to discuss any uncertainties and amend the selection criteria as needed. Any disagreements will be resolved through discussions and, if unable to reach consensus, by consulting a third reviewer.

Stage 4: charting the data (data extraction)

The reviewers will collaboratively develop a form to extract data relevant to the research question. To pilot the data extraction form, two researchers will independently fill out the form for five articles. The team will then meet to discuss any uncertainties and amend the form as needed. Following the pilot test, the lead reviewer (CW) will chart the data from the remaining articles. The data extraction form may still be amended at this stage as needed in consultation with the other review authors. If additional information from included research articles is needed, the corresponding author will be contacted via email.

It is anticipated that the following variables will be charted:

1. Descriptives about study characteristics (ie, authors, year and location of study completion, study design and methodology, sample size).
2. Descriptives about participant characteristics (ie, disability type, age, gender, severity of disability, age at and time since acquiring the disability).
3. Descriptives about peer support characteristics (ie, definition, implementation format).
4. Qualitative and quantitative data pertaining to the key outcomes of interest (ie, individuals' needs and preferences and experiences).
5. Limitations of the study as noted by the study authors.

Stage 5: collating, summarising and reporting the results

The best form of analysis and reporting of findings will be determined depending on the available data. However, it is anticipated that the results will comprise the following aspects.

Screening results related to the study selection will be presented in the form of a descriptive numerical summary and a PRISMA flow diagram.⁵⁵ Study characteristics, participant characteristics and peer support characteristics will be presented in tabular form alongside descriptive in-text summaries.

It is anticipated that most findings concerning the key outcomes of interest will be qualitative given the experiential focus of the review question. These will be analysed using thematic synthesis, conducted

according to the three stages proposed by Thomas and Harden⁵⁶: line-by-line coding of the extracted qualitative data without consideration of the review question,² collation of the codes into descriptive themes, and lastly,³ conversion of descriptive themes into analytical themes to answer the review question. Thematic synthesis is a well-established methodology for synthesising data across qualitative studies that will enable us to develop new interpretative conclusions while staying grounded in the perspectives of people with acquired neurological disability.⁵⁶ Where available, quantitative findings will be analysed separately, and overlap between quantitative and qualitative findings will be assessed. Throughout the analyses, careful consideration will be given to the context of a study's findings (ie, population and peer support type) to understand the variability of the factors identified in the review. Depending on the results, findings may be presented as a table or diagram alongside a written summary. Moreover, a list of factors important to consider when establishing peer support for adults with acquired neurological disability will be collated. Lastly, limitations described by the authors of the included studies as well as overall limitations in the literature observed by the review authors will be summarised in the text.

Stage 6: consultation (patient and public involvement)

A reference group of 4–6 people with acquired neurological disability is currently being established for a wider research programme focused on peer support. Members will be casually employed for their role in the reference group. The final stage of the scoping review will involve a consultation with this reference group.

The consultation will be conducted online as a group or individually. Prior to the consultation, a plain language summary of the review findings will be distributed to the reference group. During the consultation, members will be asked to reflect on whether the findings resonate with their lived experience as well as whether any aspects important to peer support are not covered in the included research articles. Members will also be invited to openly share any other comments they may have about the findings. Discussions from this consultation will be integrated with the review results. Lastly, the reference group members will be asked to provide recommendations regarding the dissemination of the findings beyond academic outlets, including potential dissemination avenues and formats. It is hoped this consultation will deepen the review findings, ensure the findings echo lived experience and help uncover gaps in the literature base.

ETHICS AND DISSEMINATION

An ethics approval is not required for the scoping review or consultation with the reference group. The findings of the review will help facilitate evidence-based implementation

of peer support that is guided by the perspectives of those it intends to serve. It is anticipated that the findings will be disseminated in academic journals and conferences. Other avenues for dissemination, including knowledge translation activities, will be informed by the consultation with the reference group.

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