Peer Support for Chronic and Complex Conditions

A Literature Review

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Acknowledgements

EXECUTIVE SUMMARY

1. The objectives of this literature review are to update an earlier literature review undertaken in 2011 to include more recent research articles exploring effective models of peer support; outcomes of peer support; comparative effectiveness of different models of peer support; cost-effectiveness and sustainability of peer support in the context of the value of peer support to the Victorian sub-acute and primary health care system. This literature review is not a replacement of the earlier version but may be considered supplementary.

2. As with the previous literature review, this literature review uses methods related to systematic searching. Key medical databases were searched, and literature was confined to randomised controlled trials (RCTs) and systematic reviews (SRs) reported in peer reviewed journals. Following independent review by the researchers, 33 articles were included.

3. There is a wide range of terms used to describe peer support; most articles failed to define peer support or clearly describe the model of peer support employed. Few articles demonstrated the research was related to theory or theoretical models.

4. As with the previous literature review, the current literature reviewed demonstrates shortcomings in research designs, including inability to measure 'dose-response' relationships. Short time-frames of many RCTs made it difficult to assess effectiveness of the peer support programs being tested to produce changes in health behaviours.

5. Two RCTs explored cost-effectiveness and two Systematic Reviews included cost-effectiveness studies but rated them as medium-poor quality. Two reports (CADTH and Trachtenberg) reported programs where cost-savings were made. This represents an increase in reporting on cost-effectiveness since 2011, though the generalisability of the results is limited by the standard of evidence.

6. Systematic reviews criticised RCTs of peer support published since 2011 continued to criticise RCTs, in particular for inappropriate or inadequate research designs, not reporting all the findings including adverse ones, or not explaining training programs and interventions fully. Despite these reservations, authors of systematic reviews continue to regard peer support as effective and maintain that improved research design and evaluation would demonstrate this. Authors of systematic reviews offer few suggestions on how research designs and evaluation can be improved.

7. However, many RCTs in this current review demonstrate a higher sophistication in research design and analysis than previously, suggesting some maturation in this field. There were more qualitative and mixed methods (quantitative and qualitative) studies. This is encouraging and should provide better data that leads to theory development and increased sophistication in research design and development of hypotheses that can be theoretically related to understanding underlying mechanisms of peer support and its outcomes.

8. We conclude with the following questions for further research:
    - are we researching the wrong aspects of peer support;
    - are we expecting outcomes that are not, in fact, the province of peer support, for example, changes in biomarkers for the severity of chronic health conditions;
    - is the randomised controlled trial the correct methodology to apply since it removes variables that might provide useful information about components of peer support;
    - if the randomised controlled trial is to be retained, are there more appropriate indicators to measure effectiveness of peer support than measures of health outcomes;
    - are there more appropriate research designs that will generate robust outcomes ; and capture important information about the journeys of ill people who access peer support?

1. INTRODUCTION

Peer support programs have been developed and sustained by not-for-profit health foundations in Victoria for many years. They are considered a cost-effective means to support and educate people with chronic conditions and continue to be valued by those who participate in them. However, they also have the additional advantage of allowing those who have lived with a chronic condition to share their experiences and support people who have been more recently diagnosed in their journeys towards redefining their lives. This form of support is now recognised as an important adjunct to professional health care.

In 2011, the Victorian (then) Department of Health commissioned a literature review to examine the evidence base for the effectiveness and impact of various models of peer support. This literature review found that poor research design impeded the establishment of a good evidence base. However, many systematic reviews considered peer support to be valuable to people with chronic illnesses and deserved further research in order to ensure peer support programs could best assist people with chronic illnesses take back control of their health and quality of life.

2. OBJECTIVES

This current literature review was conducted with the aim of examining whether more recent peer support research has employed better research designs and produced more robust evidence with regard to peer support's effectiveness. This review does not replace the previous literature review but builds on it with the specific objective of assessing new evidence on the effectiveness of peer support. It specifically explores literature published since June 2011 for new evidence that may shed light on which aspects of peer support are most effective; the outcomes of peer support interventions; cost-effectiveness of peer support; the sustainability of peer support programs; how peer support links to sub-acute and primary healthcare settings; and the costs and benefits of peer support peer support workers, recipients and funders.

3. METHODS

3.1 Search Terms
Two researchers (CW and EM) conducted a search of the health-related databases Medline, CINAHL, PsycINFO, PubMed and Cochrane Library, using the following terms:

Peer support + technology broad
Peer support +PAM (Patient Activation Measures)
PAM (general) RCT and Systematic Reviews
Peer support + RCT and systematic reviews
Peer support and technology (RCT and systematic reviews)

Key words

Chronic, complex, peer support, mentor, cancer, asthma, arthritis, musculoskeletal, heart disease, cardiovascular, stroke, diabetes, rural/remote, homeless, social isolation, mental health, mental illness.

Additionally, a hand search was conducted to identify qualitative research into peer support, reports and discussion papers. This was done through ResearchGate, Google Scholar and sites such as NICE UK, US-based Peers for Progress and the Canadian Agency for Drugs and Technologies in Health (CADTH).

3.2 Inclusion criteria:
The strategy was to include articles on randomised controlled trials (RCTs) and systematic reviews (SRs) from January 2011 to July 2018 in English which sampled participants from one or more chronic and complex mental or physical health populations, who engaged in peer support activities as part of their health or psychosocial management. Because social media and other technologies (mobile phone apps, interactive online programs) are now part of the peer support field, interventions that used technology were included. The initial search delivered 284 peer-reviewed articles.

3.3 Selection strategy:
After removal of duplicate results, all abstracts were read independently by CW and EM. Articles on single or small projects or those only marginally concerned with peer support issues or no evidence on effectiveness were excluded. Protocol papers with one exception were excluded as there were no results recorded. The exception relates to a protocol paper that reported pilot research for the proposed research (Horvath, Rivet Amico, Erickson et al 2018). The result was 34 articles to review in full. Eighteen of these were RCTs; additionally there was one rapid review; a qualitative study, and two reports. The remaining 11 were systematic SRs.

Another facet of the 2018 project has been to explore other methods of evaluating peer support effectiveness that do not rely solely on clinical outcomes such as HbA1c or weight-loss, as such changes may be of less value in predicting lasting behaviour change. Patient Activation Measures (PAM) are designed to capture changes in a patient's self-management and engagement in health-related activities. These were specifically targeted in a second search of literature as patient activation has the potential to evaluate the effectiveness of peer support in changing health behaviours. Methods involved in longitudinal studies were also considered since effectiveness of peer support may be better gauged over longer time-frames. Finally articles relating to Grading of Recommendations, Assessment, Development and Evaluations (GRADE) to estimate the level of evidence (very low, low, moderate and high) in these areas of effectiveness in RCTs were sourced to assist with analysis of the evidence.

Additional resources appear in the references as they were sourced for purposes of analysis and discussion.

3.4 Analysis
Complete published copies of those articles that met the inclusion criteria were obtained and read with key attributes summarised in terms of effectiveness, outcomes, sustainability, relationships and cost-effectiveness between peer support and sub-acute and primary care, costs and benefits, populations served and models of peer support. Reviewers (EM and CW) applied GRADE to the RCTs. This assists in estimating the levels of evidence including bias, limitation in research design and reporting of results as well as assisting in comparisons of research.

Our results are then compared with the results of the 2011 literature review to estimate if more recent research shows methodological improvement and offers guidance for improved delivery of peer support programs.

4. RESULTS OF 2018 LITERATURE REVIEW

The results are set out in the 2011 format for the purpose of comparing changes in evidence of effectiveness of peer support.

4.1 Use of terminology:
As with the 2011 review, there is no shortage of new terms and variation in terms across articles. Articles variously referred to "peer support"(Viiser, van Laarhoven, Woldringh et al 2016), "peer mentoring" (De Mello, Pinto, Mitchell et al 2018), "peer counsellor" (Leone, Allicock, Pignone et al 2016), "peer-based learning"(Morris, Schueller & Picard 2015), "peer workers" (Johnson, Lamb, Osborne 2018), and "peer health worker" (Fuhr, Salisbury, De Silva et al 2014). Additional terms used throughout the literature and lacking the "peer" prefix are "user led services" (Kaplan, Salzer, Solomon et al 2011), "social support" Kaplan, Solomon, Salzer et al 2014), and "lay person" (Leone, Allicock, Pignone et al 2016).

4.2 Definitions in 2018
Articles still may not define peer support adequately. Thom, Ghorab, Hessler et al (2013) distinguish between peer support, peer health coaches and peer educators, arguing that peer health coaches are more flexible than peer educators. They did not define these terms or explain why one was preferable to another. Barker & Maguire (2017) defined peer support as 'experts by experience' though experience is not specified. Similarly Ju, Shi, Yao et al (2018) referred to "experiential knowledge" and defined peer support as "the provision of support from an individual with experiential knowledge based on sharing of similar life experiences". Visser, van Laarhoven, Woldringh et al (2016) largely defined peer support by outcomes reported in the literature rather than by reference to a theory-driven construct.

Compared to the RCT literature, the systematic reviews included made greater attempts at defining their terms. However,r there was again variation in the presence and quality of the definitions provided. Shilling, Morris & Thompson Coon et al (2013) did not define peer support in their mixed methods systematic review or seek to explore the range of definitions in the articles they included. Haines, Beasley, Hopkins et al (2018) cited Pfeiffer, Heisler, Piette et al (2011), defining peer support as 'bringing together non-professionals with similar stressors or health problems for mutual support or unidirectional support from an experienced to novice peer". Bartone, Bartone, Violante et al (2017) cited Mead, Hilton & Curtis (2001) in defining peer support as a "System of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful…". Fuhr, Salisbury, De Silva at al (2014) defined "peer health workers" as providers of conventional health services who carry out a variety of tasks such as counselling, case-management and advocacy in mental health services.

4.3 Theories relating to peer support
Some articles did not elucidate a theoretical basis for peer support. Of the RCTs included in this review, only seven stated a theoretical orientation. Four of these only stated a nominal reference to theory, with a minimal association between theory, mode of delivery and outcomes (Kaplan, Salzer. Solomon et al 2011; Kaplan , Solomon, Salzer et al 2014; McCusker, Lambert, Cole et al 2016; Visser, van Laarhoven Woldringh et al 2016). Only one study (Ju, Shi, Yao et al 2018) reported on a theoretical foundation that included some description of core features, mode of delivery, and a reference to proposed mechanisms or 'active ingredients' of peer support. No article provided a detailed, theoretically derived description of peer support, hypothesised methods of effect, or the relationship between delivery, outcomes and the theoretical basis.

De Mello , Pinto Mitchell et al 2018 specifically stated that their research was based on social cognitive theory and the transtheoretical approach. Houlihan, Brody, Everhart-Skeels et al (2017) applied the health empowerment approach as well as social cognitive theories.

Social support theories posit social connectedness assists people in their recovery while social learning theory developed by Bandura (1977) theorises that people learn from others who act as role models. Bandura's theories have been expanded by others to social identity theory (Shubert & Borkman, 1994; Breen, Karangoda et al (2017) which argue that people learn better from those they identify as similar to themselves so that peer support provides motivation through inspirational role models. Bartone, Bartone, Gileno et al (2018) in their qualitative review of peer support for bereaved people discussed the theoretical background for peer support but failed to link this theoretical model to an explanation of how, why and under what circumstances shared experiences may work. Barker & Maguire (2017) explored 'intentional peer support' for people experiencing homelessness. They identified the common elements of successful programs such as shared experience and role modelling. This provided a testable hypothesis to refine current models of effective peer support

4.4 Research design
The RCTs varied in the quality of design. The majority clearly reported inclusion and exclusion criteria and cited original research. Only one (Houlihan, Brody, Everhart-Skeels et al 2017) had a design that effectively demonstrated outcomes that could be attributed to peer support. Other studies reported general differences between the intervention and control groups, though these differences could have been associated with influences other than peer support. Only five studies reported blinding of researchers involved in data collection and analysis. The majority of studies were powered to produce an effect. Four studies used intention to treat analysis in order to control for bias attributable to participant attrition.

4.5 Training
In 2011 we reported that descriptions of training of peer supporters were important in order to assess and compare research results. However, as in 2011, many RCTs, and consequently fewer SRs, provide details. Eleven RCTs reported that peer workers were provided training, while 10 of them provided details. Forms of training varied widely between studies.

Another issue is that training needs to be consistent in order to ensure consistent results when programs are delivered by several peer supporters across multiple sites. Wu, Chang, Courtney et al (2012) reported consistency as an issue. In this research, several researchers trained peer supporters independently and this led to inconsistent work by peer supporters. This was rectified by having one researcher undertake all training.

When training is described, it most often featured a training manual, didactic sessions largely to ensure information is presented in its intended form, communication skills and role plays. Some training also instructed peer supporters to assist support group participants to develop their own action plans to achieve personal goals. Thom, Gorab, Hessler et al (2013) provide a good example of this in their RCT: peer coaches received 36 hours of training over eight weeks, with an online curriculum, and involving small group didactics, role plays, observations, action planning and practice sessions. Other researchers included ongoing supervision sessions for peer supporters (De Mello, Pinto, Mitchell et al 2018).

Morris, Schueller, & Picard, (2015) provided peer supporters access to a series of three to five minute training modules on empathic responding. Other studies reported provision of training across a range of peer support skills areas, including listening skills, supportive feedback, cultural

awareness, self-disclosure and confidentiality, and social support (Johnson, Lamb, Osborne et al (2018); Leone, Allicock, Pignone, 2016; Westerhof, Lamers, Marloes, 2017). Some peer suporters were also provided with training specific to clinical or technical aspects of the intervention including motivational interviewing, identification of cognitive distortions, cognitive reframing, or online moderation (Leone, Allicock, Pignone, 2016; Morris, Schueller, & Picard, 2015). Only one study provided peer supporters with ongoing supervision, (Johnson, Lamb, Osborne, 2018).

Only one article specifically mentioned that formal training was not considered necessary because peers worked from their experience.

There were no reports of evaluations of the training provided and its role in influencing results and no study reported on whether training added value to the outcomes.

One systematic review (Bartone, Bartone, Violante et al 2017) pointed to the need for training and supervision to safeguard the well-being of peer supporters working with bereaved people. They reported adverse events such as over-involvement by peer supporters with the bereaved while some of the participants did not respond positively to the support that was offered. Bartone, Bartone, Gileni et al (2018) conducted a qualitative review of peer support for bereaved people to develop the features of best practice in peer support for bereaved people. They recommend that a feature of best practice is thorough training. Training needs to include cultural competency (knowing the cultural background of those you work with), listening skills, training to assess risk levels in participants including when to refer to clinicians, knowing the boundaries of peer support and having ongoing training. The authors emphasised ongoing monitoring is very important. Stubbs, Williams, Shannon (2016) also recommended that peer supporters be provided ongoing support. Peer supporters should also know when to seek help or respite for themselves as well as using other peer supporters as their own support group.

5. VALUE OF PEER SUPPORT

5.1. Effectiveness
5.1.1. Randomised controlled trials (RCTs)
Of the RCTs reviewed, seven studies focused on peer support for physical health conditions (including preventative and early intervention), and six focused on mental health conditions. Of the studies focusing on physical health, one reported on support for breast feeding of preterm infants (Niela-Vilen, Axelin, Melender, et al (2016), with the others researching colorectal cancer screening (Leone, Allicock, Pignone et al (2016), medical-service engagement of women identified at high genetic-risk for breast cancer (Visser, van Laarhoven, Woldringh et al (2016), and support for treatment following breast cancer diagnosis (DeMello, Pinto, Mitchell et al (2018). For existing conditions, two trials targeted individuals diagnosed with Type II diabetes (Gillespie, O'Shea, O'Dowd, & Smith (2012); Ju, Shi, Yao et al (2018), and one focused on individuals with chronic spinal-cord injuries (Houlihan, Brody, Everhart-Skeels et al 2017). Outcome measures were varied, ranging from ratings of uptake of screening services (Leone, et al, 2016), satisfaction with service engagement (Visseret al, 2016), to changes in biomarkers for Type II diabetes (Gillespie, O'Shea, O'Dowd, & Smith, 2012; Ju, Shi, Yao et al (2018).

Two of seven studies examining effects of peer support for physical health conditions found effects as hypothesised for peer support: Houlihan, Brody, Everhart Skeels et al (2017) reported increased patient activation, increased satisfaction with life, decreased social/role limitation, but with greater change in participants who reported higher levels of social support at baseline. This study also

reported adequately powered analysis, researcher blinding, and use of a control group, permitting the attribution of the results to the peer support intervention over the provision of matched health-care information. In the context of Type II diabetes, Ju, Shi, Yao et al, (2018) reported significant decreases in fasting plasma glucose and diabetes-related distress (including emotional burden, physician-related distress and regimen-related distress), but no change in other diabetes-related biomarkers such as HbA1c or postprandial blood glucose. In the context of breastfeeding of preterm infants, recipients of peer support reported greater usefulness of peer support over midwife advice, and influence of peer support on their breastfeeding, but no change on measures of breastfeeding attitudes or expression of breast milk, indicating that preference for, and perceived utility of, peer support did not translate into behaviour change (Niela-Vilen, Axelin, Melender et al (2016).

De Mello et al (2018) explored the effectiveness of peer supporters in a 12-week physical activity program for women with breast cancer. At the end of the program, the intervention participants more closely resembled the peer supporters in their exercise activities. However, the control group also showed some improvements, possibly due to engagement in the Reach to Recovery program and telephone calls they received. The authors note that the control group might have also engaged in physical exercise.

Of the RCTs that focused on mental health populations, two examined outcomes of peer support for individuals with severe mental illness or 'psychiatric disability' (Kaplan, Salzer, Solomon 2011; Kaplan, Solomon, Salzer 2014), one looked at outcomes for individuals following receipt of acute mental health crisis support (Johnson, Lamb, Osborne 2018), and three looked at outcomes for individuals with either depressive symptoms or diagnosis of Major Depressive Disorder (McCusker, Lambert, Cole 2016; Morris, Schueller, & Picard, 2015; Westerhof, Lamers, Marloes 2017). Of the six studies examining effects of peer support for mental health conditions, four reported positive effects in line with hypotheses. Johnson, Lamb, et al, (2018) reported significantly higher satisfaction with mental health care received at four-month follow up, and significantly reduced rates of readmission to acute care in the year post-crisis; however,r there were no differences in outcomes at 18 months. Kaplan, Solomon, Salzer et al (2014), investigating peer support for mothers with diagnoses of severe mental illness, reported marginally significant gains in parenting and coping skills, but no improvement in perceived social support or parenting efficacy. Morris, Schueller, & Picard, (2015) reported that a peer-support intervention delivered via an internet-based messaging board was associated with change in depression-related cognitive reappraisal, and more visits to the online platform (despite fewer posts). This did not translate into differences in depressive symptoms or perseverative thinking. McCusker, Lambert, Cole (2016) reported gains in activation and self-efficacy in individuals with major depressive disorder, but the gain was not significantly greater to gains also observed in the control group. Similarly, Westerhof, Lamers, Marloes et al 2017 reported no significant differences for reductions in depressive symptoms with both the intervention and control groups improving in depressive symptoms. However, and importantly, reductions in depressive symptoms were maintained at six-month follow-up *only* in the peer condition.

Finally, Thom Ghorab, Hessler et al (2013) conducted an RCT on peer support and glycaemic control, training peer supporters who delivered the intervention to people with Type 2 Diabetes and poor glycaemic control which was compared with a control group receiving usual diabetes care. While both arms improved in glycaemic control, the intervention group did better. The authors considered the results demonstrated the value of peer support for low income groups.

5.1.2. Systematic reviews
Of the systematic reviews published since 2011, the reviews covered a wide range of contexts and conditions, including peer support interventions provided to homeless individuals (Barker & Maguire., 2017), sudden bereavement (Bartone, Bartone, Violante 2017), chronic pain (Bender,

Radhakrishnan, Diorio et al 2011), physical activity (Burton, Farrier, Hill et al 2018), risk-factors for cardio-vascular disease (Patil, Ruppar, Koopman et al 2018), and health-related behaviours of individuals with severe mental illness (Stubbs, Williams, Shannon et al 2016).

Burton, Farrier, Hill et al (2018) conducted a systematic review and meta-analysis exploring the effectiveness of peer support in exercise programs for older people. They considered the results equivocal due to the small sample sizes in the research included for review and recommended higher powered samples and greater consistency of measures across studies that would permit a higher number of studies to be included in meta-analysis. However, they noted that peer support appeared to improve adherence to exercise programs, with the increased social engagement provided by peer supports valued by older people'

Canadian Agency for Drugs and Technologies in Health (CADTH 2013) reported on both clinical and cost- effectiveness of peer support. This rapid review noted poor evidence across studies for both effectiveness and cost-effectiveness. In clinical effectiveness, the main outcome measures for peer support in heart disease and type 2 diabetes and HIV were glycaemic control, cholesterol, self-efficacy, knowledge of condition, physical exercise, risk behaviour, adherence and quality of life. Two of six RCTs in heart disease found statistically significant effectiveness, while research in HIV found peer support assisted sexual risk behaviour.

5.2 Cost-effectiveness
CADTH found only one cost-effectiveness study but it did not include all risk factors related to Type 2 Diabetes. Burton, Farrier, Hill et al (2018) found six studies mentioning cost-effectiveness, only one of those providing some evidence that peer led programs were as effective as professionally led programs and thus cheaper. Gillespie et al (2012) conducted an RCT of group peer support in managing Type 2 Diabetes in primary care to measure cost-effectiveness. They maintained that, despite the lack of improvements in pathology results, peer support was probably cost-effective. Trachtenberg et al (2013) inferred that lower bed usage meant peer support was cost-effective. Similarly, the results from Johnson, Lamb, Marston et al (2018) RCT showing fewer acute mental health care admissions following their peer-to peer intervention might be used to infer cost-effectiveness.

Small, Blicken, Blakeman et al (2013) conducted a systematic review of telephone-based peer support to gauge clinical effectiveness and cost-effectiveness of this management strategy in vascular disease. Positive effects for this approach were found in improving self-management in diabetes control but poorly designed RCTs limited the results.

Shilling, Morris & Thompson-Coon (2013) conducted a systematic review and meta-analysis on the benefits of peer support for carers of children with chronic illnesses. Their focus was on the lasting effects of peer support as well as its cost-effectiveness in terms of health service usage. They included both quantitative and qualitative papers. Small sample sizes were identified as an issue in RCTs. Four themes were explored: social identity, learning from the experience of others, supporting others, and personal growth. These themes were seen to be generic to experiences of peer support across carers of children with different conditions.

Thom, Ghorab, Hessler et al (2013) conducted an RCT on peer support and glycaemic control, training peer supporters who delivered the intervention to people with Type 2 Diabetes and poor glycaemic control which was compared with a control group receiving usual diabetes care. While both arms improved in glycaemic control, the intervention group did better. The authors considered the results demonstrated cost-effectiveness of peer support for low income groups.

5.2 Peer support and mental health programs

Peer support is still used and valued in mental health programs. Fuhr, Salisbury, De Silva et al (2014) conducted a systematic review on the effectiveness of peer support in severe mental illness and depression programs and found that participants gained a sense of optimism in the short term from their peer supporters. Health service usage was not impacted. Barker & Maguire (2016) explored peer support for homeless people in a systematic review and found that it had a positive effect on reducing drug and alcohol use as well as improving physical and mental health and life skills. Stubbs, Williams, Shannon (2016) conducted a systematic review on the value of peer support in improving physical health outcomes for people with serious mental illnesses and concluded that the results in this area were equivocal and were adversely affected by the small sample sizes and inconsistency in outcomes measures in the research. Westerhof, Lamers, Marloes (2017) conducted an RCT using a complex online intervention with only 58 older people. Results showed that both intervention and the control group improved. Some participants reported their dislike of the intervention.

Stubbs, Williams, Shannon (2016) conducted a systematic review on peer support's potential to improve physical health of people with serious mental illnesses. The number of publications was small, and results reported little improvement, but as with many reviews, the authors argue that peer support has the potential to assist and better research needs to be conducted.

Morris, Schueller &Picard et al (2105) developed an app featuring CBT for use by people with depression, hypothesising that a level of active engagement would be better than passive engagement. This RCT had a small number of participants and demonstrated this intervention group enjoyed the peer to peer interaction. The resulting publication provided a valuable description of the problems in undertaking this research and reported adverse events and riskiness of the process. Johnson, Lamb, Marston et al (2018) recruited 220 people following discharge after an acute mental health episode. The intervention and the training of peer supporters were well-described as were the methods of evaluating the results. While acute admissions dropped, the number of days in acute care was not reduced.

Kaplan, Solomon, Salzer et al (2014) and Kaplan, Salzer, Solomon et al (2011) undertook RCTs using bulletin boards, listserv and email for people with mental illnesses. While people received training in using the technology, both the training and the intervention was poorly described. It was reported that those who registered the most satisfaction with the process also had higher distress levels. The reasons behind this finding were not determined, and the authors argued there was need for more research to identify effective online support interventions. In 2018 it is likely that use of listserv and bulletin boards have been replaced by smartphone apps.

5.3 Peer support and smart devices

Peer support programs involving devices are now well established and subject to research (Morris, Schueller & Picard (2015); Stubbs, Williams & Shannon (2016). Horvath, Rivet-Amico, Erickson et al (2018) conducted RCTs on the feasibility and effectiveness of online peer support in medication adherence for HIV patients. Much of the intervention program seemed to be focussed on information given from a website but there were opportunities for men to share their experiences. Authors conclude that the site fostered peer support for some participants which was appreciated, but its aim to increase medication adherence was patchy. Bartone. Bartone, Violanti et al (2017) reviewed peer support programs for bereaved people and found that, while online programs were valued for their accessibility, there was little difference in outcomes between them and face to face peer support. Hopwood, Walker, McDonagh et al (2017) conducted a systematic review of online support programs for carers of people with dementia which were valued for their accessibility. Twenty-five of the studies had peer support as a central feature. Results demonstrated that support

received from peers, either as open messages or privately through email or a messaging service, was greatly valued. Other examples were of videoconferencing and chatrooms. Results demonstrated improvements in mental health of carers and reductions in feelings of social isolation.

Kingod, Cleal, Wahlberg et al 2017 conducted a qualitative review of online programs for people living with chronic Illnesses. This review did not focus on effectiveness in terms of health improvements or service usage, but in terms of the meanings for those with chronic illnesses who are engaged in peer support. Houlihan, Brody, Everhart-Skeels et al (2017) conducted an RCT on telephone coaching by peers to research self-management in people with spinal cord injuries. This was a small trial of 42 people in each arm over six months and showed it had positive effects on preventing secondary conditions. The short timeframe of the trial, however, would suggest that this result is questionable.

5.3 The positive peer support experiences of participants

Many articles comment on the positive experiences of people in peer support. Barker & Maguire (2017) explored the effects of peer support on homeless people in their systematic review. They found that participants reported peer support provided social support, assisted with skills development and, in some instances, reduced the number of homeless days. In some research, peer support improved quality of life and assisted people deal with mental health and drug addiction. Bergin, Grogan, Bernshaw et al (2016) found that the participants with gynaecological cancer in a small pilot project enjoyed peer support but noted that the effectiveness of the project could not be ascertained. Burton, Farrier, Hill et al (2018) reported that the social aspect of peer support was an attraction to engaging in physical exercise. Bartone, Bartone, Violante et al (2017) reported that this social interaction was regarded positively by both participants and the peer supporters in bereavement. There were reports of the value of peer support by those who had experienced post-traumatic stress from bereavement. Participants reported reduced symptoms of depression and social isolation, increased perceptions of personal growth, wellbeing, and making sense of their loss. Peer supporters reported increased sense of personal growth, satisfaction in helping others and the sense of 'giving back' as a means of generating something good from their own loss. However, this review also highlighted the role of shared identity and perceived similarity of experiences needed to benefit from peer support. For example, bereaved fathers found it more difficult to benefit from participation in female-dominated support programs.

In some instances (Westerhof, Lamers, Marloes (2017); Kaplan, Solomon, Salzer et al (2014), participants reported dislike of the process because they did not feel well-supported, became more distressed by the intervention, or disliked sharing with strangers. Thom, Ghorab, Hessler et al (2013) in their study of peer health coaches to improve glycaemic control suggested that finding out more about people's preferences for coaching and the qualities of peer coaches would be valuable for future programs.

5.4 Summary of findings

The literature review of 2011 demonstrated that, due to poor quality research design, the small sample numbers involved in RCTs and the short timeframes, any conclusions on clinical effectiveness was questionable. In 2018 this is still the case.

- There is no seminal definition of peer support that has been adopted by the majority of researchers.
- Theories of peer support are not routinely used to underpin research into peer support.
- The lack of a theoretical foundation for peer support means that research varies widely in what it is measuring as an outcome of peer support.

- Clinical measures such as HbA1c in diabetes are favoured as the principal surrogate means of measuring effectiveness in behaviour change in chronic conditions.
- Research projects are often conducted over short time frames which do not provide evidence of any lasting effects, particularly in changes to behaviour.
- Systematic reviews struggle to identify verifiable results from projects and RCTs.
- Peer support continues to be seen as valuable and cost-effective despite the poor results associated with clinical measures.   It is seen as particularly valuable in mental health.
- Consumers and carers register their support through attendance and by becoming peer supporters.
- A small number of articles explored cost-effectiveness of peer support based on reduced hospital stays and admissions. Other articles inferred its cost-effectiveness when unpaid support substituted for professional care, allowing paid staff to do other tasks and reducing hospital stays.
- The current literature review contains suggestions for further research.

6. DISCUSSION

The results suggest that there has been small progress in establishing evidence for the effectiveness of peer support. RCTs still have problems regarding their design, recruitment and their outcome measures. Even when well-designed, results are often less than significant. Cost-effectiveness since 2011 has received more attention in the literature but must be tempered by the lack of evidence on outcomes.

As in 2011, enthusiasm for the role of peer support in chronic conditions continues, most notably in mental health.

The results identify areas where improvements can be made to assist gathering evidence of how and why peer support works.

6.1 Definitions and Theories
Definitions are important because they name the essence of the thing to be examined. If this is not done, it leaves others to make their own inferences. In something such as peer support where there is no standard definition, its meaning may vary from one researcher to another. As we see from the results, some definitions assume that peer support is integral to personal experience of illness and recovery while others relate it to observable outcomes or applications of training and education. Those research projects that commence with a defined account of what peer support is, will be moving towards some internal consistency and contribute towards the evidence-base.

A working theory of peer support makes clear how and by what mechanisms peer support may benefit the participants. This may then be applied as a working hypothesis in the different situations where peer support is employed.

Theories applied to peer support, as well as other health care interventions are most often related to individual behaviour change, though this appears overlooked by the focus on use of clinical indicators as measures of changes in behaviours regrading both physical and mental health conditions. Glanz & Bishop (2010) argue here is increasing evidence of the effectiveness of health promotion interventions based on broader social and behavioural theories. Oyserman, Fryberg & Yoder (2007) maintain that social identity theory has potentially important applications to understanding psychological mechanisms that influence peer support outcomes.

Davis, Campbell et al (2015) consider the evidence is mixed and may be due to poor application of theory or employment of an inappropriate theory. They also suggest theories including social and environmental factors should be considered. Glanz & Bishop (2010) stress the most successful programs will take into account the contexts in which those programs are instituted, rather than only concentrating on developing personal skills, knowledge and changing belief patterns. Alternatively, Michie, van Stralen &West (2011) argue that the science of behaviour change needs to be improved. Instead of deciding on the broad reach of behaviour change and then designing the specific interventions, it is important to consider all options and then choose rationally from them, while considering the target population and the social context in which the program will be delivered.

"Theory drives research. It serves as a guide for knowing what variables to measure, how to measure them, and how to combine them. It also serves as a framework for aiding researchers in developing and evaluating intervention approaches. If a researcher believes that existing theories are inappropriate or incomplete, he or she can extend upon an existing theory or create a new theory altogether."

S. M. Noar and R. S. Zimmerman (2005) Health behaviour theory. Are we moving in the right direction?
Downloaded from https://academic.oup.com/her/article-abstract/20/3/275/854464

Davis, Campbell et al (2015) argue that, to understand behaviour change, it is necessary to have a theory of behaviour change. A theory will contribute to more rigorous applications and evaluations of interventions, will allow a better understanding of how behaviour change produces the effects, and will summarise the accumulated knowledge in this area. As evidence is collected, a theory may advance or, as Noar and Zimmerman (2005) note above, should a theory prove less fruitful, it can be replaced.

6.2 Training
The centrepiece of delivering effective interventions that drive behaviour change in peer support programs is the training of peer supporters to deliver theory-based content. Cane, O'Connor & Michie (2012) reinforce this view when they argue that there "is some evidence that behaviour change interventions informed by theory are more effective than those that are not." However, they maintain that in reality, designs of such training are more likely to be based on "common-sense models of behaviour." In this current literature review, it is evident that many of the research designs pay less attention to training, its design, delivery, and theoretical basis of training content. There is little information regarding whether training was formally accredited, that it meets standards of a vocational training authority or is informal, being independently developed for purposes of the research or a "common-sense" program that has been developed over time to fit circumstances of those requiring peer support. Where a program is delivered across multiple sites such as in primary care, consistent training is required to provide consistent results. Monitoring of its delivery to ensure intervention fidelity is also required; otherwise, it may not always be delivered as it was designed or adhere to the research protocols developed to produce consistent and unbiased results (Walker, Furler, Blackberry et al 2011).

There is little evaluation of training reported in these programs. The value of evaluations can be seen in self-management programs. These processes are transferable to evaluating training in peer

support programs. For example, Kennedy, Rogers, Chew-Graham et al (2014) undertook a process evaluation of a self-management program in UK primary care. This evaluation used a multi-method approach in line with the UK Medical Research Council recommendations to explore what worked and did not work for organisations, the staff, and patients. Normalisation Process Theory (NPT) was used as the basis of design and the results of the evaluation were included in the results of the main trial. The evaluation found that training was expected to be undertaken by entire practices and was "facilitative" rather than didactic. Practices were unfamiliar with this form of training and no single practice member was in a leadership role. These were identified as barriers to its consistent and effective delivery of the training to patients.

Research in the fields of self-management or peer support in health care is acknowledged as a complex intervention where the aim is to produce behaviour change. At the same time delivery, of the intervention takes place in complex environments, where complex behaviours already exist. Examples are the delivery of peer support to homeless people, many of whom had mental health issues or drug addictions (Barker & Maguire 2017); and the use of peer support to improve breast feeding rates amongst mothers of pre-term babies in a neo-natal intensive care unit – a complex environment in itself, but where staff and the participants possess diverse beliefs and views about breastfeeding including feelings of guilt (Niela-Vilen, Axelin, Melander et al 2016).

6.3 Are we expecting something that peer support can't deliver?

6.3.1 Raising the questions

Authors of systematic reviews both in 2011 and 2018 pointed out that the design of RCTs and their disappointing results have not provided good evidence for the effectiveness of peer support. Within the current literature review, some authors speculated on the disappointing results and suggested that there were other aspects of peer support that might be more rewarding to investigate, for example, who most benefits from peer support (Furh, Salisbury, de Silva et al 2014), why it is popular with people with chronic illnesses,and which aspects are popular (De Mello, Pinto,Mitchell et al 2018; Small, Blicken, Blakeman et al 2013), and concentrating on improvement in psychosocial wellbeing rather than clinical physical outcomes.

> "*First, what measures of health outcomes are theoretically appropriate, and plausibly consistent with what should be expected as proximal to the effects of peer support as an intervention? Second, is there evidence to support the responsiveness of the selected outcome measure scale to be able to detect important health change in this context? Third, what time-frames are appropriate, both in terms of the duration of peer support as an intervention and time elapsed before follow-up assessment of outcome? Finally, what is appropriate for use as a control comparator in this context? That is, is it appropriate to ask parents to wait for support, and how and if it is ethical or necessary in a pragmatic trial to prevent parents from seeking other types of support in addition to the study's own intervention?*" Shilling, Morris & Thompson-Coon (2013).

These questions arise because, despite the poor results, views that peer support has value in managing chronic physical and mental conditions remain,. This value is seen in the numbers of people world-wide who engage with peer support, either formally or informally (for example, see the work of Peers for Progress). Thus it becomes important to ascertain both how peer support contributes to improved wellbeing and develop programs that strengthen these aspects. Kingod, Cleal Wahlberg et al (2017) emphasised the value of online support and 'identity work'; Bergin, Grogan, Bernshaw et al (2016) noted that, despite the poor results, participants still liked the program, while Niela-Vilen, Axelin, Melender et al (2016) reported that 73% of breast-feeding mothers preferred advice from peer supporters over advice from midwives.

In 2017 the World Health Organisation quotes Solomon's 2004 article on the benefits of peer support:

> *The benefits of group peer support are wide-ranging and can include the provision of a safe environment to freely express and share emotions and thoughts about one's current situation and challenges; sharing of information and experiences and learning from others in similar situations that can help provide ideas and solutions to overcome challenges that group members are facing; the opportunity to build new relationships and strengthen social support networks which helps to reduce isolation and feelings of loneliness; sharing of knowledge about available community resources and practical support to help group members access resources and support, for example, helping others complete administrative procedures to access social and disability benefits, employment programs and so on.* Creating peer support groups in mental health and related areas - WHO QualityRights training to act, unite and empower for mental health (pilot version). Geneva: World Health Organisation; 2017 (WHO/MSD/MHP/17.13)

6.3.2 Appropriate research designs

The above quotes suggest that research designs need to be rethought. RCTs, as they are now employed in peer support research, are essentially reductionistic, in this case reducing peer support, to pre-determined component parts (Hawe, Shiell & Riley 2004). Variables that may play a part in the success or failure of a program are discounted at the outset so do not figure in the results. Randomisation, which is meant to produce intervention and control groups that are identical at the outset of a research project, may be based on clinical and demographic factors (diagnosis, age, medical interventions and clinical results) and will ignore personalities, beliefs and behaviours, all of which will impact on results. This means that the results are not always transferable to the 'real-world', since different contexts and actors will produce different outcomes. Overall, reductionism relegates possibly important variables to background 'error' so they are not evaluated for their influence on the outcomes in peer support.

Another issue that suggests the unsuitability of RCTs relates to the time frame. RCTs take place as 'snap-shots'; they are time-limited, sometimes as short as several weeks in duration. If we accept that health behaviours are not only complex but built up over time, sometimes over generations, then expecting them to produce immediate change, or that any changes will show immediate clinical outcomes may be unrealistic.

Hawe, Shiell &Riley (2004) suggests that, instead of trying to create laboratory conditions, it would be better to start by examining all the variables present to understand the complexity of a system in order to understand how an intervention will work. Similarly, the UK MRC Developing and evaluating complex intervention (2019) recommends a thorough understanding of the contexts and the various parts of a complex intervention, as well as starting from a theoretical base. This gives coherence to the intervention and allows for replication. Piloting is important as well as building in a process evaluation. It is only after much preparatory work that a researcher considers which research design to adopt. Other recommendations include mixed methods studies to ensure that both quantitative and qualitative data are captured. Additionally, longitudinal research which compares changes over time has the capacity to show more effects of peer support on a range of indicators, including self-efficacy, social connectedness, and clinical outcomes. A longitudinal study can collect statistical and qualitative data. Caruana, Roman, Hernandez-Sanchez et al (2015) maintain it is particularly useful to showing changes in outcomes of treatment over varying periods of time, for either a whole group or the individuals within the group. This is highly advantageous for demonstrating cause and effect. They might be undertaken as repeated cross-sectional studies,

though each study tends to capture a 'snap-shot' and compare them, rather than show changes within the same cohort. An example of the application of longitudinal research comes from Canada where data about the relationship between parental support and physical activity patterns amongst 22, 909 adolescents over three Waves of data collection was explored. This demonstrated, that where parental support around physical activity decreased, there was a decrease in physical activity. This was further supported by showing that, when parental support in this area increased, physical activity of adolescents also accordingly increased (Lau, Faulkner, Qian 2016).

Pawson & Tilley (1997) have been prominent critics of the use of RCTs in researching complex interventions involving human behaviour. They have argued for 'realist' evaluations, which don't assume direct causal links between interventions and outcomes but examine contexts in order to establish "what works for whom and when". They argue that outcomes are realised as the interrelationship between context and the intervention. Thus they argue for exploring what works for whom and in what contexts rather than simply determining that something does work.

Bonnell, Fletcher, Morton et al (2012) present a case for retaining the RCT, albeit in a form that synthesises the 'realist' approach (Pawson and Tilley 1997) and accounts for what mechanisms work within specific contexts. This is set out below:

Randomized trials of complex public health interventions generally aim to identify what works, accrediting specific intervention 'products' as effective. This approach often fails to give sufficient consideration to how intervention components interact with each other and with local context. 'Realists' argue that trials misunderstand the scientific method, offer only a 'successionist' approach to causation, which brackets out the complexity of social causation, and fail to ask which interventions work, for whom and under what circumstances. We counter-argue that trials are useful in evaluating social interventions because randomized control groups actually take proper account of rather than bracket out the complexity of social causation. Nonetheless, realists are right to stress understanding of 'what works, for whom and under what circumstances' and to argue for the importance of theorizing and empirically examining underlying mechanisms. We propose that these aims can be (and sometimes already are) examined within randomized trials. Such 'realist' trials should aim to: examine the effects of intervention components separately and in combination, for example using multi-arm studies and factorial trials; explore mechanisms of change, for example analysing how pathway variables mediate intervention effects; use multiple trials across contexts to test how intervention effects vary with context; draw on complementary qualitative and quantitative data; and be oriented towards building and validating 'mid-level' program theories which would set out how interventions interact with context to produce outcomes. This last suggestion resonates with recent suggestions that, in delivering truly 'complex' interventions, fidelity is important not so much in terms of precise activities but, rather, key intervention 'processes' and 'functions'. Realist trials would additionally determine the validity of program theory rather than only examining 'what works' to better inform policy and practice in the long-term.
Bonnell C, Fletcher A. Morton, M et al (2012) Realist randomised controlled trials: a new approach to evaluating complex public health interventions. Soc Sci Med 75(12):2299-306

In practical terms, this would include multiple groups receiving interventions as well as a group acting as a control and then comparing the results. It would also include examining more immediate impacts such as improvement in knowledge or self-efficacy rather than changes to health behaviours which might be the goal. This has the advantage of identifying effective 'ingredients' of an intervention. Another inclusion might be conducting research across different contexts, using consistent measures in order to assess how the intervention results vary with context.

The UK Medical Research Council (2019) has developed a document on conducting research in complex interventions which lists various models of research, including natural experiments, implementation research, stepped wedge design, preference trials and evaluations.

6.3.3 Measuring peer support

Once the components of effective peer support are identified it becomes possible to consider measures that will track changes in health behaviours and associated behaviours within a peer support group or program. Changes in health outcomes such as HbA1C or using the 6 Minute Walking Test (6MWT) or weight loss may not take place immediately so that using these as measures fails to register any changes. As stated above, outcomes that may be measured in the short term as an outcome of effective peer support, may be improvement in knowledge, self-efficacy, engagement in one's own health care, or more social involvement. Patient Activation Measures (PAM) have the ability to measure such behavioural changes produced by peer support which are indicative of their potential benefits to health and their application can measure progress or otherwise in behaviour changes.

> *"On its own, patient activation as measured by the PAM provides a useful and robust assessment of a patient's ability to engage with their health care, which in turn can be a reliable indicator of a number of health outcomes. More importantly, patient activation is changeable, and targeted interventions have been shown to increase it. An overview of patient activation 16 Supporting people to manage their health 1 2 3 4 5 6 A number of programmes have demonstrated the ability to raise activation scores in patients. These typically focus on the patient gaining new skills or mastery and encouraging a sense of ownership of their health, often using peer support, changes in the patient's social environment, health coaching and educational classes."*
>
> Supporting people to manage their health: an introduction to patient activation. Hibbart and Gilburt King's Fund 2014. file:///I:/Projects/HCSG/HCSG%202018-2019/supporting-people-manage-health-patient-activation-may14.pdf

6.3.4 What gets forgotten?

Some of the articles in this review mention that, despite the poor health outcomes, participants reported enjoying participating in peer support. As a result, this suggests that it is important to understand the components of peer support from the participants' points of view and what they derive from their participation.

Much has been written about the value of social support in health (for example, see Wilkinson and Marmot 2003). Social connectedness (being married, having family, friends, neighbours, community memberships, and employment) contributes to better health outcomes. Much has also been written about the effects of illness in changing a person's life circumstances (sometimes leading to social isolation through job loss, inability to participate in the community, family and marital breakup). Such changes impact on individuals' self- esteem, their motivation and their identity (for example, see Frank 2013 and Walker 2010). While an illness will impact individuals differently, the impact will be a life-changing moment in each person's life. Frank in The Wounded Storyteller (2013) discussed the effect that an illness can have on a person's identity and he portrays the need to tell one's own story as a quest towards healing oneself and arriving at a new point where the illness is integrated into one's identity. Personal journeys are highly variable and acknowledge that life changing events may be stressful and affect physical health and functioning (Rios R, Hjemdal O, Martinez Uribe P et al 2014). Seeking social support including peer support may be one part of these personal journeys towards new identities and will influence health outcomes.

Research articles reviewed here rarely discuss the need for new sources of social support as the motivational basis for a person participating in peer support, or where in a personal journey, peer support fits. As variables these are both under-rated and dismissed. In fact, reports of enjoyment might be indicators of a journey towards future health and quality of life improvements, or at least better health self-management, following the development of new social networks.

Related to this are the dropout rates from some of the RCTs. Reasons for dropouts are rarely explored, raising the question of the circumstances for individuals' leaving. This might include that the program did not meet people's individual needs. Individuals' goals are rarely addressed.

What makes a peer support program attractive to participants was another component that received little attention, which may also impact on recruitment and drop-out rates. Murray E, Treweek S, Pope C et al (2010) in discussing designing research projects for complex interventions, which would include RCTs of peer support, argue that successful recruitment for trials is difficult and up to one third fail to reach their target number. Their solution to this is that trials need to be grounded in clinical practice because this saves researchers time in recruiting. There is no discussion of making the trial attractive to participants.

Much of these intrinsic values that are usually dismissed are effectively summarised by Kingod, Cleal, Wahlberg et al (2017) as important factors in people's lives.

"Through their online interactions, individuals with chronic illness _animated illness associated identities_, sought and provided _social support and connectivity_, shared experiential knowledge only available from those living with particular chronic illnesses, while also mobilizing collective voices for the purposes of promoting otherwise neglected perspectives concerning life with chronic illness.

A key finding is that the longing for mutual solidarity and emotional support in relation to the day-to-day management of illness _motivates_ people with a chronic illness _to seek advice and inspiration among peers with the same condition_. Identity work in the wake of a chronic illness is not a new phenomenon and has been described in several studies across different illness groups." (Kingod, Cleal, Wahlberg et al 2017).

7. CONCLUSION

In conclusion, this literature review demonstrates that peer support research continues to concentrate RCTs using clinical measures to assess clinical outcomes as was evident in the earlier review.

The poor evidence arising from this methodology raises several questions:

Is the randomised controlled trial the correct methodology?
RCTs attempt to isolate variables as well as establishing control and intervention groups that are the same at baseline. This works in laboratory research but is fraught with problems when applied to human behaviour.

Are we researching the wrong aspects of peer support?
The short time frames of much research in peer support may not capture the prolonged and sometimes emotionally draining journey an ill person takes towards personal goals. Seeking peer support may be undertaken with different goals in mind, for example, to achieve the goal of new

social connectedness. This in turn may then benefit health outcomes at certain points in an individual journey.

From this perspective health outcomes might be incidental to peer support and may only occur when peer support is doing what it does best, that is providing a safe and supportive place to deal with the emotions of having an illness, which in turn allows people to absorb information and explore new directions in their lives.

These aspects could be captured within the RCT methodology by using other measures, for example, Patient Activation Measures (PAM) or self-efficacy and social connectedness measures.

Some articles emphasise that peer support takes place within complex contexts. Improvements in clinical outcomes might not occur if there are other matters occurring in people's lives over which peer support or health professionals have no control. If support is seen to be a value in its own right, then understanding and measuring that value becomes the main point.

Some of the systematic reviews suggest that evaluation methods need to capture the components of peer support, that is, what components of peer support contribute to good outcomes, how it works, how it might be replicated in peer support programs.

Finally, while RCTs inform researchers that changes have taken place, they do not necessarily explain the "why" or "how"; these are often inferred.

This raises the question of whether there are other research methods that will more effectively explore these components, while capturing the complexity of circumstances in which experience their health and illness. More explicitly, other methods may more effectively explain the contribution of peer support. Longitudinal studies, which measure changes over time of peer support participation and might include changes to clinical indicators as well as PAM and social connectedness, are one method, while process evaluations using qualitative methods can run together with a RCT. Purely qualitative methods might assist to establish which components of peer support are effective and lead to training programs which are then subject to RCTs.

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