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<th><strong>Title</strong></th>
<th>Peer Support – Options and Effectiveness</th>
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<td>This review examines literature relating to peer support, to consider the effectiveness and potential relevance of peer support as a means of addressing the isolation sometimes experienced by people who dialyse at home and those who care for them.</td>
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Summary

Aware of the isolation sometimes experienced by people who dialyse at home and those who care for them, this review sought to learn from peer reviewed literature whether peer support is an effective means of meeting social and emotional needs, and the most constructive approaches for establishing peer support. Discovering the paucity of research that addresses peer support for people with renal disease, studies of peer support for people with long term conditions are examined.

This is not a systematic review. It is based on a broad scan of peer reviewed literature between 2000-2010 that addresses peer support for adults with long term conditions (excluding addiction), where the goal includes provision of social and emotional support. Earlier studies were included where particularly relevant. Studies of peer support that aimed to achieve educational or behavioural outcomes but that did not include social and emotional goals were excluded.

The literature on peer support for people with long term conditions is heavily dominated by peer support for people with cancer, especially breast cancer. It is valid to question whether findings from these studies are relevant to dialysis patients, but in the absence of other evidence they provide the best available guide.

There are numerous approaches for providing peer support, aiming to achieve a wide range of goals. In this review different models of peer support are delineated, reviews described, and outcomes summarised. Essentially, models vary by mode of delivery (face to face, online or telephone); format (one to one or group); homogeneity (gender, disease or condition specific or generic); duration (number of meetings, time over which spread, or ongoing); group leadership (peer or professional); intended outcomes (in addition to social and emotional outcomes goals include changes in physical health, psychological health, quality of life and financial outlay).
Reported outcomes from peer support are confusingly diverse, demonstrating no clear guidance about effectiveness or approach. Individual studies often report positive outcomes but most good quality randomised controlled trials (RCTs) and systematic reviews report mixed, neutral or negative outcomes.

On closer inspection the majority of individual studies lack adequate description, are methodologically weak in design, or both. Reviews that combine outcomes from multiple studies are hampered by varied follow-up periods; many studies report outcomes only directly after the intervention. Summation is further eluded when, as in most reviews, individual studies aim for multiple varied goals.

An interesting paradox emerges where descriptive studies tend to report positive comments from participants, but studies that apply quantitative measures often show small, non-existent or negative results. Some individual studies that report both descriptive and quantitative outcomes demonstrate such apparently contradictory results from the same participants. While seemingly inconsistent, these mixed findings highlight a discrepancy at the heart of many peer support studies. While peer support participants may be satisfied to gain a sense of normalcy and connectedness from shared experiences, peer support organised for research purposes is often aimed at more far-reaching outcomes, such as measurable changes in health-related behaviours, incidence of depression, or use of services. The essential question then, is whether peer support is intended as an end in itself, or whether it is only considered effective if it achieves other nominated ends.

Wider questions remain. Although studies demonstrate only small negative outcomes from peer support, with no evidence of lasting damage, few studies look for negative outcomes and the great majority collect data only from participants who reach the end of an intervention. Little is known about participants who cease to attend.

Peer support conducted for research purposes is not necessarily representative of peer support in general. Most studies focus on professionally rather than peer led support, and many are better supplied with skills and resources than peer support in a normal setting.

Additionally, studies that enquire into attractiveness of peer support demonstrate that, even when well publicised, invitations to participate in peer support are not widely accepted; attendance appears to be influenced by socio-demographic characteristics. Finally, very few studies report on costs of providing peer support.
In summary, there are few good studies addressing peer support that aims to meet the social and emotional needs of people with long term conditions. Before assessing the evidence it is crucial to clarify the intended aim of peer support. If the aim is primarily to provide social and emotional support for participants, descriptive studies provide many accounts of satisfaction. If social and emotional support is intended as a route to achieving more indirect outcomes in emotional or physical health and associated behaviours, there is little evidence to suggest this can be reliably achieved.
Executive summary

1 INTRODUCTION

1.1 Content of the review
This review examines literature relating to peer support, to consider the effectiveness and potential relevance of peer support as a means of addressing the isolation sometimes experienced by people who dialyse at home and those who care for them.

1.2 Scope and limitations of this review
The review is based on an initial search of peer reviewed literature from the past ten years addressing peer support for adults in the context of long term conditions. It is not a systematic review. It does not include studies of peer education where the goal does not specifically include emotional support.

1.3 Definitions of peer support
There are many definitions of peer support. One that is commonly cited describes it as comprising emotional, appraisal and informational assistance. Other definitions emphasise the importance of only limited input from health professionals and the central role of shared experience.

1.4 Overview of literature
Very few peer reviewed articles were found on peer support in the context of dialysis or renal disease. The literature on peer support for long term conditions is dominated by peer support in the context of cancer, heavily weighted towards breast cancer. Very few studies have been conducted in England. The literature on peer support is generally acknowledged to be methodologically weak. It is not known how realistic it is to generalise findings on the effectiveness of peer support from one health condition to another. Needs of those who dialyse at home may differ from those represented in studies reviewed here, but in the absence of studies on peer support for dialysis patients the existing literature provides the best evidence available.

2 MODELS OF PEER SUPPORT

2.1 Models, variables and options
There are many different models of peer support. This review identifies six variables, with different options.
2.2 Mode of delivery: face to face; online; telephone
The first variable is the mode of delivery. While most peer support is face to face, peer support is also provided on the internet or by telephone.

2.3 Format: one to one; group
Most research reports on group-based peer support but peers also can act as peer supporters in one to one programmes.

2.4 Homogeneity/specificity: gender, condition
The literature on peer support has a strong focus on cancer, and particularly breast cancer. As a result many of the studies consider women-only interventions. Other single-sex programmes occur, outside of gender specific diseases, but more are mixed. Most groups are disease specific.

2.5 Duration: number of meetings and time over which they are spread
One to one peer support may involve a single meeting to share information, though some 'buddying' programmes continue much longer. Group support reported in the literature typically runs for three to nine sessions, with each session lasting about 90 minutes. Some reports describe groups that run for up to a year, but studies rarely address groups that are ongoing.

2.6 Group leadership: peer or professional
Research studies are heavily biased towards peer support facilitated by one or more health professionals. When self-help groups are led by peers generally those leading the group undertake some degree of training.

2.7 Intended outcomes
This review only included studies that aimed to deliver a social or emotional outcome. Across the studies a variety of social and emotional goals are sought. Some studies aim to achieve and measure outcomes in additional areas including physical health, psychological health and health-related quality of life.

3 AIMS, INTENDED OUTCOMES, THEORIES AND MECHANISMS ........................................

3.1 Aims of peer support
Approaches to delivering and evaluating peer support are wide-ranging and there is no meaningful generic peer support model. One distinction can be made between support provided by peers, or peer support with professional input. The former is likely to aim for emotional and informational support. Peer support with more professional input often incorporates a wider range of goals including educational, behavioural or physical outcomes.
3.2 Intended outcomes and ways of measuring them
Outcomes assessed in evaluative studies of peer support can be grouped in many ways: here they are described in eight categories. Perceived social support is the first area, relating directly to peer support. It can be described qualitatively and there are some quantitative scales. Second, emotional outcomes include levels of mood disturbance, depression, anxiety, hope, adjustment to illness. Measures include BDI, HADS and POMS. Third, self efficacy relates to confidence and sense of control, tools exist to measure this. Fourth, knowledge and understanding of illness and disease and treatment options. Fifth, health behaviour, often relating to self management skills. Six, health outcomes. Seven, use of health services is measured in studies that include an economic component. Eight, health-related quality of life is measured in some studies, using SF-36 or other tailored quality of life scales.

3.3 Underpinning theoretical models
Two main theoretical models underpin the concept of peer support: social comparison theory, and stress and coping theory. Other relevant perspectives include the helper therapy principle, and modelling as a way of increasing self efficacy.

3.4 Mechanisms
The three components of peer support: emotional, affirmational and informational support are the essential mechanisms by which peer support operates, though professionals leading groups may add therapeutic, educational or other components.

4 IMPACT AND OUTCOMES OF PEER SUPPORT

4.1 Diverse spread of findings
Studies of peer support report conflicting findings about its effectiveness.

4.2 Reports of positive outcomes
Some studies, particularly descriptive and one-group studies, report positive outcomes from peer support. Participants appreciate mutual sharing and common experiences which develop a sense of belonging, normality, hope and confidence. One systematic review reports entirely positive outcomes.

4.3 Reports of neutral or negative outcomes
Many of the more thorough studies including Randomised Controlled Trials (RCTs) report mixed outcomes, sometimes with no evident improvement beyond the control group, and occasional adverse outcomes. Four thorough systematic reviews report mixed outcomes.
5 POTENTIAL EXPLANATIONS AND INTERPRETATIONS OF MIXED FINDINGS............

5.1 Common observations across studies
Comments from four thorough systematic reviews of peer support help interpret the mixed findings.

5.2 Methodological limitations
Reviews of peer support literature commonly report problems with study design and description. Typical weaknesses include lack of theoretical framework, inadequate programme description, response rates not based on intention to treat, lack of information about non-participants, use of non-validated measures, small numbers of participants, and use of multiple outcome measures. These methodological flaws limit confidence that can be placed in findings from many studies.

5.3 Lack of long term follow up
Most studies report findings measured immediately after the intervention or up to three months later. Few extend to a year or longer. Studies that do measure outcomes at a later date show no consistency in whether outcomes have improved or deteriorated, though overall more diminish. Lack of agreed expectations about length of time outcomes should persist highlight lack of clarity around outcome measures more generally.

5.4 Lack of clarity about outcome measures
Despite mixed outcomes from peer support evaluations, generally qualitative descriptions and quantitative measures of immediate outcomes related to peer support, such as availability of social support, reduced isolation and satisfaction with service show positive findings. Where outcomes are sought for changes less directly linked to peer support, eg changes in depression or health-related behaviour, there is less evidence of success. It is reasonable to question whether these are reasonable outcomes with which to measure the effectiveness of peer support.

5.5 Individual differences
Peer support is not universally attractive and is not the first choice of support for many people. Even when well informed about availability of peer support many opt not to use it. People who do use peer support tend not to be representative of the target population; they are generally younger, middle class, better educated, married and employed. One study that found better outcomes for those who participated in peer support demonstrated that when socio-demographic variables were controlled for the effect of peer support participation was no longer significant. Other studies suggest that support groups work best for those in greatest need, meeting emotional or informational deficits in the participants’ existing networks or services. Some studies suggest that individual coping style plays a factor in determining effectiveness and appropriateness of peer support; others claim that stage of
illness influences the style of support needed. With so many potential variables unaccounted for a lack of consistent findings seems inevitable.

6 APPROACHES TO DELIVERING PEER SUPPORT: IMPACT ON OUTCOMES ...............  

6.1 Challenge of refining findings
Most reviews combine a range of models for providing support. Here, each of the six variables identified in Section 2 is considered separately, in an attempt to clarify potentially effective approaches. Studies for the less frequently examined approaches are often small with limited capacity to demonstrate statistically significant findings.

6.2 Mode of delivery: face to face; online; telephone
Face to face studies are the most common so are best considered with other variables. Only one internet-based study showed negative outcomes. Participants in this study were all recently diagnosed, giving them no opportunity to gain benefits from views of long term survivors. Other internet-based studies found moderate levels of interest and varied levels of use, tending to peak at two or three months then diminish, though individual rates of use vary considerably. Access and availability at the time of greatest need is a key benefit for internet based support. Risk of damaging outcomes are noted but none are reported. Participants often report positive feelings about internet based groups, but there is little statistically significant evidence of success.

Telephone studies are an under-reported area. As with internet-based groups no negative outcomes are reported, and there is no evidence of outcomes beyond the immediate ones of satisfaction and an appreciation of the sense of not being alone.

6.3 Format: one to one; group.
One to one peer support requires coordination to recruit and train peer supporters, match them with those wanting to use the service, and maintain the scheme, Concern has been expressed about potential overburdening of peer supporters while the helper therapy principle suggests they may benefit. No quantitative evidence of benefits to supporters was demonstrated in studies reviewed here but qualitative responses indicated beneficial outcomes. Uptake of one to one support may depend on the time at which it is offered. Two large scale studies offering one to one support at time of diagnosis show good, though far from universal rates of uptake. In both studies participants expressed satisfaction with the service, no further outcomes were measured.

6.4 Homogeneity/specificity: gender, condition
Gender-specific groups are common, weighted heavily towards groups for women with breast cancer. Internet gender specific groups demonstrate stereotypically gendered
communication styles. No studies reviewed here compared outcomes of single or mixed sex groups.

While claims have been made that the more homogenous peer relationships are the more effective they can be, others report that a mix of newly diagnosed participants and long term survivors is needed. Studies showing that those who start a group in a stronger position benefit least and may experience adverse effects (possibly temporarily) raise questions about the overall benefits of mixed groups. Yet, as the internet study cited above demonstrated, a group of participants all in similar positions of need may find few opportunities for hope.

6.5 Duration: number of meetings and time over which they are run

There is no reported evidence on ideal duration of support for maximum effectiveness. The varied range of follow up periods among studies helps conceal any association between duration of intervention and success rate. Some authors comment that the more effective interventions are those that operate over a longer period, possibly six to 12 months.

6.6 Group leadership: peer or professional

There is minimal reporting of genuinely peer led support. Though views are mixed the weight of opinion is towards professionally led peer support, and some studies report a definite preference amongst potential participants for professional leaders. Two main benefits of professional leadership are information accuracy and maintenance of positive group culture.

6.7 Intended outcomes.

The wide range of intended outcomes sought and measured brings with it conflicting and sometimes paradoxical results, where, in some cases participants describe positive outcomes while demonstrating no benefit or adverse outcomes on measurement scales. Possible explanations include invalid qualitative reports; invalid quantitative tools; and/or inappropriate outcome measures. Choice of outcome measure relies on clarity about the underlying aim: is peer support is an end in itself, or a means towards other ends. Outcomes that demonstrate increases in perceived support, satisfaction with services and other direct outcomes from the intervention may or may not be adequate markers of success, depending on the aim. Much of the confusion in interpreting findings comes from conflating results relating to immediate, direct outcomes with those relating to less direct outcomes (such as quality of life or self efficacy). Apart from the possibility of unreliable or invalid measurement scales, inadequate dose of the intervention and too short a follow up period, unless logical progression from the immediate outcome to the intended one can be demonstrated, failure to achieve positive outcomes may reflect poor programme logic rather than inadequacy of peer support.
7 REALITIES, RISKS AND BENEFITS

7.1 Realities

Three questions can be asked to relate findings from the literature to the real world. First, how representative are studies of peer support of those in the real world? The bias in research towards professionally led groups has been noted. Also, research studies often establish groups and invite participants, or allocate them by random assignment based on disease or demographic data. The impact of this selection process on group functioning and outcomes is not known. Also, there is a tendency for RCTs to operate in close to optimal conditions not reflective of the real world, thereby demonstrating efficacy rather than effectiveness.

The second question asks how significant these findings are in the real world. Relatively low uptake of peer support must be borne in mind, and the tendency for participants to come from a specific section of the community.

The third question relates to financial or other costs. Little is reported about financial costs and ongoing maintenance. Voluntary groups aiming to establish peer support need to consider carefully the amount of input required.

7.2 Risks

Few adverse effects have been demonstrated. Those that have appear small or short-lived, but little attention has been paid to identifying adverse effects. Those who drop out of peer support are rarely followed up. Many challenges are reported by support group leaders or those concerned about negative outcomes from peer support, particularly in groups. Challenges include member conflicts, dealing with death of group members, and upsetting discussions. Few studies reviewed here considered the potential for the key theoretical models to operate in reverse, with social comparison theory resulting in diminished sense of self efficacy; stress and coping theory demonstrating lack of availability of support; and helper therapy principle resulting in the peer supporter being overburdened. Effective group leaders may lessen these risks. They may also be less significant for online groups or one to one support, though research evidence is particularly limited in these areas.

7.3 Benefits

Descriptive accounts from participants of peer support commonly report direct benefits including a sense of mutuality, belonging, normality, access to relevant information, and increased ability to cope. Quantitative measures of satisfaction can also be demonstrated. Participants who reach the end of a series of sessions are inevitably those most biased towards appreciative comments. Their views are not representative of those who chose not to attend or who dropped out. Nevertheless, undeniably some people who attend peer support perceive themselves to have benefitted. Lack of clarity or diverse views about
worthwhile outcomes from peer support leaves open the question about whether these perceived benefits are adequate, whether measureable outcomes in other more indirect areas should be demonstrated, what proportion of the target population should benefit for peer support to be considered worthwhile, what risks will be taken and what costs incurred.
1 INTRODUCTION

1.1 Content of the review

Peer support is a concept with broad appeal and wide application. This review was prompted by the wish to address the isolation often mentioned by those who dialyse at home, and the challenges faced by those who care for them. The aims of the review were to clarify the range and type of approaches to providing peer support, to identify aims and potential outcomes, to assess the impact and effectiveness of peer support, and to explore and identify factors associated with success in achieving aims.

1.2 Scope and limitations of this review

This is not a systematic review; it is based on a broad scan of recent peer reviewed literature using search terms: ‘support group’, ‘peer support’ and ‘self help group’, initially with terms relating directly to haemo/hemo or peritoneal dialysis and then with long term/chronic conditions or disease, and carers, searching for evidence of effectiveness. The search was conducted in the Cochrane Library’s Database of systematic reviews, DARE, NHS ECONic Evaluation database, and in HEED, and on Medline, Embase, Cinahl and Psychinfo. Literature from any country in the past ten years was searched, so long as available in English. References from earlier years that appeared particularly relevant were also accessed.

Based on an initial scan of abstracts full text was obtained for articles that addressed issues of direct interest. Only studies that focused on adults were included and only those that included social and emotional support as an intended aim. Studies of peer support with entirely educational or behavioural aims were excluded, as were those that address addiction. Methodological rigour was taken into account: in keeping with accepted levels of evidence, findings from well-conducted systematic reviews and well-designed Randomised Controlled Trials (RCTs) were given more significance than those from controlled trials without randomisation or before-and-after studies without controls.

Although this review was established to explore peer support in the context of home dialysis the minimal number of studies addressing peer support for people with renal disease led to a broader study of peer support for people with long term conditions. The literature is heavily dominated by peer support for people with cancer, particularly breast cancer. The relevance

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1 Many thanks to staff from Bodleian Library for conducting literature searches.
of these findings for people who dialyse at home is not known, but in the absence of more specific research the studies reported here provide the best available evidence.

1.3 Definitions of peer support

The three descriptions below include common themes in the understanding of peer support but also illustrate differing emphasis on the various components and ways in which peer support is provided.

Peer support is the ‘provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person’. (Dennis 2003)

‘The key characteristics of self care support networks are that they have limited health professional involvement and the aim of the group is not purely to educate or train, but rather to support by giving and receiving advice and practical help to other network members’. (Woolacott et al 2006).

‘A self help group is run mainly for its members by its members. They must do something together about a common problem [such as the experience of cancer]. Professionals and other people do not normally get involved. The group is not anti-professional, but the emphasis in the group is the experience [of cancer]. Members feel that by helping others they are helping themselves and they control decisions. (Cancerlink booklets 1988-1999, cited in Clark et al 2000. Brackets added.)

Some of the differences implicit in these three descriptions are described in the following section.

1.4 Overview of literature

Well over half of the articles identified by searches for this review addressed support groups for people with cancer, breast cancer forming by far the largest category. There were few studies focusing on carers. Searches of peer reviewed literature since 2000 found only two studies (Hughes et al 2009, Chen et al 2007) that addressed peer support in the context of people using dialysis. Very few of the studies were conducted in England.

| 2 | The spread of type and topic of peer support reviewed in the literature is not necessarily representative of frequency or type on the ground. Quantity or quality of reviews of particular types of peer support may be influenced by availability of research funding and/or amenability to monitoring and evaluation. |
Two immediate observations emerge from the literature. The first is the diversity of approaches for providing peer support. The second is a common lament about the inadequacy of design, description and evaluation quality in most studies of support groups. Many authors agree that the combined effect of diverse approaches and inadequate evaluation limits the extent to which it is possible to generalise from the literature.

This review aims to outline issues of broad agreement and to highlight areas of uncertainty.

2 MODELS OF PEER SUPPORT

2.1 Models, variables and options
Some authors, while reviewing peer support, devise their own taxonomy of models of peer support as they describe the topics covered in their study. The following is by Dunn et al (2003): professionally supervised dyadic, face-to-face setting; professionally supervised group, face-to-face setting; professionally supervised group, remote setting; peer-supervised group, face-to-face setting; and peer-supervised group, remote setting.

Key approaches for providing peer support are listed below, indicating a range of variables and options within them. The effectiveness of peer support may be influenced by the choice of approach.

2.2 Mode of delivery: face to face; online; telephone
While meeting face to face remains the most commonly reported approach for peer support there are some studies of online support groups. Telephone-based support is sometimes used for one to one support and there are some reports of telephone support groups.

2.3 Format: one to one; group
The majority of studies that inform this review reported on groups rather than one to one peer support. Hoey (2007) comments on the small proportion of studies reviewing one to one or telephone support. Groups typically range from four – twelve participants, though some are much larger.
2.4 Homogeneity/specificity: gender, condition
A large portion of the studies on peer support, particularly those for people with cancer, address support groups specifically for women, largely because of the predominance of support groups for breast cancer\(^3\). Groups specifically for men are less frequent but do occur. Because of the search terms used, groups included in this study were all disease or illness focused, most for a specific disease and some for a specific stage of the disease, but a small number had broader inclusion, for example, cancer of any type (Docherty 2004) and a support group for relatives of terminally ill cancer patients (Witowski & Carlsson 2004).

2.5 Duration: number of meetings and time over which they are spread
One-to-one peer support sometimes, by choice, involves a single contact only to share information, though it may continue much longer. Groups reported in evaluation studies typically meet between three to nine times over a period of roughly one to three months. Very occasionally groups may run for up to a year. A common meeting length is about 90 minutes. Other than online networks no groups included in this review were ongoing, all comprised a pre-defined number of sessions. The duration of peer support reviewed in the literature is not necessarily representative of that on the ground, the need to evaluate and report potentially biases the type and duration of support that appears in the literature.

2.6 Group leadership: peer or professional
Self-help groups are led by peers who have undertaken varying levels of training in facilitation or group leadership. Peer support groups are facilitated by one or more people with advanced training in health or social sciences, such as nurses, physicians, social workers, psychiatrists, mental health workers or other professions relevant to the intended outcome. Most studies focuses on professionally led groups.

2.7 Intended outcomes
All studies covered by this review included a social or emotional component as part of the intended outcome. Other outcomes frequently included and sometimes measured are those relating to physical health, psychological health, self-efficacy and quality of life.

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\(^3\) Zabalegui et al (2005) note that 70% of the reports on support groups for cancer that they reviewed were specifically for breast cancer. Hoey (2007) and Cambell (2004) make similar observations.
3 AIMS, INTENDED OUTCOMES, THEORIES AND MECHANISMS

3.1 Aims of peer support

Woolacott et al (2006) aptly summarise the difficulty of describing peer support, concluding a comprehensive systematic review of the evidence of the clinical effectiveness of self care support networks in health and social care by stating: 'the characteristics of the interventions that have been studied suggest that no clearly definable generic self care support network type intervention exists.' (Woolacott et al 2006: xvi).

A distinction may be drawn between support provided by peers for peers with shared experience (self care or self help), and support groups led by one or more people with professional expertise in a topic relevant to the group. The former involve little or no professional input and the identified aims, usually determined by members, are likely to include some or all of the following: emotional support, informational support, practical help within or outside the group, and advocacy.

Clark et al (2000) list the following aims nominated by a self-help group for men with testicular cancer: to provide information and support; to instigate professional education; to act as an advocate for services to meet men’s needs more appropriately; and to disseminate testicular awareness information where possible.

By contrast, support groups for women generally place more explicit emphasis on emotional support rather than the information and action-oriented aims that men often state.

Support groups led by professionals incorporate a wider variety of identified aims. Alongside emotional or social support they may identify educational, behavioural, psychological, health-related or economic aims.

3.2 Intended outcomes and ways of measuring them

Despite the conceptual distinction between, on the one hand, self care groups and on the other, support groups led by professionals, intended outcomes for both types of groups reported in research studies cover broadly similar ground.

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4 Requirements for journal publication are likely to influence the types of group most frequently reviewed, and prompt a leaning towards measurable outcomes.
Authors categorise outcomes in varying ways. Categories listed by Murray et al (2005) comprehensively cover outcomes addressed in most studies under the following headings: social support; emotions; self-efficacy; knowledge; health behaviour; health outcomes; resource utilisation. Few individual studies cover all categories. Quality of life is a broad measure that includes aspects of several of the headings listed above.

Qualitative studies thematically categorise and describe outcomes while quantitative studies measure specified outcomes, ideally using validated scales, some of which are disease or condition specific.

Considering in more detail items included under each heading, outcomes for social support rely on qualitative statements or measures of perceived social support or social isolation. Perceived social support is difficult to measure. There is no one accepted scale; studies often devise their own.

Aspects of emotional outcomes reported by different studies include levels of mood disturbance, depression, anxiety, hope, adjustment to illness or disease and marital satisfaction. Measures frequently used include Beck's Depression Inventory (BDI), the Hospital Anxiety and Depression Score (HADS) and Profile of Mood States (POMS).

Self-efficacy relates to a sense of confidence and control. Scales for self-efficacy are generally adapted to the specific situation to which they apply.

Knowledge, including information about and understanding of illness or disease, and of possible treatment options is condition specific.

Health behaviour, often with a focus on understanding and/or applying self-management skills, is also condition-specific, as are health outcomes, measured by self-assessment and/or clinical measures.

Use of health service resources is measured in studies that include an economic component.

Health-related quality of life is sometimes measured with the SF-36 (which can be broken down into physical functioning and mental functioning scores) or a specially tailored Quality of Life Scale (QOLS).
3.3 Underpinning theoretical models

Campbell et al (2004), in a review of cancer peer support programmes, comment on the lack of reference in most studies to the explanatory theoretical models that underpin the concept of peer support. An understanding of the models is important for designing appropriate evaluation and to alert programme leaders to potential areas for improvement or dysfunction.

In common with Campbell et al, Gottlieb & Wachala (2006) identify two key theoretical perspectives of particular relevance to peer support. Social comparison theory claims that when under perceived threat people seek company, especially of those facing similar circumstances, to compare the appropriateness of their thoughts, feelings and behaviour. As they discover that others in similar circumstances experience comparable feelings and thoughts people experience a normalising effect. Group members can engage in upward, downward or lateral comparisons. Generally people make the type of comparison that enhances their self concept and improves their behaviour.

The second perspective, stress and coping theory, claims that the perceived availability of coping resources provides a buffer against stress. When people believe that informal support is available they fare better psychologically. Under this theory it is not only actual support from which people benefit, but the growing belief that support is available.

There are other hypotheses about how social support brings benefits. The ‘helper therapy principle’ claims that people gain good feelings about themselves by being useful to others, which they are given the opportunity to do in support groups. Another explanation is that the group allows participants to learn and model coping skills from other participants and/or leaders. As they do so they build confidence in their ability to cope, enhancing their sense of self-efficacy. Finally, the opportunity to express emotion in itself has a stress-reducing effect, allowing people to process their feelings at a deeper level and adjust to their situation more effectively. Some support groups may provide that opportunity.

3.4 Mechanisms

Whatever the underlying theory, essentially the key mechanisms by which peer support operates are described by Dennis (2003) in her definition of peer support as emotional, appraisal and informational assistance.

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5 Some authors (eg Docherty 2004) include practical assistance as a key function. In fact most practical assistance is informational; assistance is only rarely instrumental.
To expand further, Dennis describes the category of emotional support to include expressions of caring, encouragement, attentive listening, reflection and reassurance. It generally involves avoiding criticism or advice-giving. The effect is to foster a sense of being accepted, cared for, admired, respected, valued and empathised with.

Appraisal support, also described as affirmation support, involves affirming the appropriateness of emotions, cognitions and behaviours; giving motivational encouragement and reassurance; and generally communicating optimism and positive future expectations (Dennis op cit).

Dennis describes information support as the provision of knowledge relevant to problem-solving, including information about relevant resources, alternative courses of action, guidance about effectiveness and independent assessments about problem aetiology. Helgeson et al (2000) describe the underlying aim of information as being to enhance control over the illness experience.

Women’s groups are generally described as focusing on emotional and affirmational support (Sullivan 2003) though some level of information sharing is generally involved (Ahlberg & Nordner 2006). Similarly, while men’s groups often focus on information and/or activities (Sullivan 2003, Clark et al 2000) emotional support can be developed and expressed, albeit in different ways to in women’s groups (Adamsen 2001).

Professionally led support groups may include additional components or mechanisms, such as skills training, therapeutic activities, or specific educational components, but the three aspects described by Dennis are operative in most descriptions of peer support, to varying degrees.

4 IMPACT AND OUTCOMES OF PEER SUPPORT

4.1 Diverse spread of findings
Not only is there a wide range of approaches to providing peer support, there is also a wide range of views about their effectiveness.

A major contributing factor to the difficulty in determining how effective peer support might be is the weak structure, description and analysis of many of the evaluation studies. Key
challenges in interpreting reported outcomes from studies are discussed below (Section 5.1) but a central gap is the lack of long-term follow up for most studies.

4.2 Reports of positive outcomes

Some studies of peer support cite only positive findings from literature on the topic (Bui et al 2002, Chen et al 2008, Clark et al 2000). Equally, many studies report only positive findings from their own research. For example Ahlberg & Nordner (2006) describe the support and sense of care that women (n=10) with ovarian cancer experienced in the support groups they joined. Based on qualitative findings from interviews conducted with participants (most interviews were conducted 5-19 weeks after the final session) they report that the feeling of ‘being in the same boat’ as other patients who share the experience of cancer may be a tool that supports coping.

Adamsen et al (2001), as noted above, report positive outcomes from a support group for men with cancer (n=10) that offered physical activity followed by information sessions. Using data gathered from participant observation and focus groups the authors report that the men experienced collective reciprocity, developing a subculture in which the feeling of being different was removed. ‘What links the group together is the shared confidence of its membership and the unconditional acceptance of one another. This helps to bridge the gap of isolation and provides the individual with a feeling of being in control.’ (op cit:533).

Chen et al (2008) in one of only two studies found for this review that relate specifically to people using haemodialysis6, report on a mutual support group in Taiwan. Fifteen haemodialysis patients were recruited to a newly established support group that met eight times in three months. No information is provided about the basis on which participants were selected. Two weeks after the sessions ended participants were asked to complete questionnaires that they previously answered prior to starting the course. The questionnaires, using scales developed by one of the authors, measured physical symptoms, social support and quality of life. Outcome effects for all three areas were shown to have significantly improved, however there was no control group for comparison and no further follow up.

While there are many more small studies reporting positive outcomes7, the following systematic review of RCTs is unusual in also finding overwhelmingly beneficial results.

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6 The other is Hughes et al (2009) reported in 4.3.
7 In some cases positive reporting in the abstract of an evaluation is not a comprehensive reflection of findings in the body of the report.
Zabelegui et al (2005) conducted a meta-analysis of RCTs relating to group support in cancer patients in the previous 20 years. The authors report that studies with poor methodological quality were excluded as were those without enough power to combine with other studies, leaving 20 RCTs which they reviewed. Analysing the outcomes for impact on depression, anxiety, quality of life, adaptation, and marital relationships the study found positive results in all areas. It was only in the area of increased survival that the analysis failed to find a positive outcome. The study concludes that overall ‘it appears that there is a beneficial effect of psychosocial interventions in support groups for oncology patients, improving their emotional state and their illness adaptation. However the psychotherapeutic techniques and the formats of individual and group interventions vary.’ (op cit:378).

4.3 Reports of mixed, neutral or negative outcomes

More mixed accounts of the benefits of peer support are reported in some descriptive evaluations, in studies that measure quality of life, in good quality RCTs and in systematic reviews. It is often noted that while peer support programmes found benefits for some participants, others demonstrated inconclusive or adverse outcomes.

Hughes et al (2009) report on the only UK-based study found for this review that addresses peer support for people with chronic kidney failure. An individual peer support programme was established in two teaching hospitals in London offering one to one support to renal patients from other trained kidney patients. The aim of the programme is to offer information and short term emotional support in one or two individual meetings or telephone conversations, but not to establish a longer term relationship. The programme is operated by a link nurse in each hospital who organises training for volunteers, maintains a record of trained peer supporters and matches them to those requesting support, promotes the scheme to clinicians, and manages the volunteers⁸.

To evaluate the programme twenty renal patients who had received support were purposively selected by the link nurses to provide a mix of age, gender, ethnicity and reasons for using the service. Each was interviewed by telephone. Of the 20, 18 were entirely positive about their experience of the service and two were entirely negative. Almost all had only one meeting with their supporter. Those who commented positively about the service appreciated it as a way of accessing practical information about treatment for kidney disease and hearing about the lived experience. Some commented on the reassurance of

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⁸ A full report of the programme can be found at http://www.gsttcharity.org.uk/pdfs/whitecoat.pdf
knowing they were not alone in what they felt; others felt that reassurance came from seeing
others coping with similar challenges to their own. The two who reported negative
experiences described feeling anxious and frightened after meeting their peer supporter. The
scope of the study did not allow for further investigation of the extent or cause of their
negative experience.

Messmer Uccelli et al (2004) evaluated an eight week peer support programme for people
with multiple sclerosis. Six groups of seven people each met weekly, led by a trained peer
facilitator. There was no control group. Facilitators were guided with a training manual, of
which participants had an adapted version. Prior to starting the programme and again at the
end each participant was sent a battery of questionnaires to self complete, measuring quality
of life and depression. Some patients showed improvement but not all. When the group was
divided by severity, patients that started with lower quality of life and greater levels of
depression showed improvements in these areas. Patients with better mental health
functioning showed some deterioration, though the small sample size and lack of control
group limits the extent to which these findings can be seen as clinically significant.

Prins et al (2001) designed a multi-centre randomised trial to test the effectiveness of CBT
for people with chronic fatigue syndrome. Patients (n=270) were sequentially assigned to
one of three conditions: CBT; support group; control. The CBT groups met for 16 one hour
sessions over eight months. Thirteen behavioural therapists including psychologists,
psychiatrists and health scientists contributed to the CBT group. Support groups, each with
approximately eight participants, met 11 times for 90 minutes over eight months. A social
worker was available for members of the support groups. The aim was to offer mutual
understanding and recognition through exchanging experiences. The control group received
no intervention. Drop-out rates for CBT and support groups were reported as high. At the
end of eight months, and again at 14 months patients were assessed for fatigue severity and
functional impairment (primary outcomes), and for psychological wellbeing and quality of life
(secondary outcomes). Significantly different treatment effects were found for all items
between CBT and support group participants, with support group participants showing no
improvement over the control (no treatment) group. Nevertheless, 80% of patients said that
they experienced mutual understanding in the support group and rated contact with the
therapist and atmosphere in the group as good. Such positive comments, unmatched by
positive outcomes, led Prins et al to suggest that patient satisfaction and clinical
improvement are not correlated and may be independent.
Helgeson et al [2001; 2000] report on a trial of peer support for women recently diagnosed with breast cancer (n=230) who were randomly allocated to groups that provided either education alone, education with peer discussion, only peer discussion, or control (no intervention). Seven groups of eight to twelve women met eight times for each of the conditions, except the control group. The aim of the education group was to provide expert information, enhancing women’s control over their illness experience; interchanges with other women were limited to avoid contamination with the peer discussion model. Peer discussion groups were facilitated to focus on expression of positive and negative feelings and self-disclosure. The combined group started with education and ended with discussion.

Participants in each group were asked to complete the SF-36 before the intervention began, one or two weeks after the end of the eight sessions, six months later, one year later, and two years later. Average time elapsed between the first and last interview was 40 months.

Overall comparison of findings from the four groups at the end of the eight sessions showed consistent positive effects from education only and an overall adverse effect from peer discussion alone. There was no overall benefit for education combined with peer discussion.

Analysis of findings from peer discussion groups at an individual level at the end of eight sessions showed that women who lacked emotional support from their partners gained some benefits in their physical functioning score. By contrast, women in peer discussion groups who, at the outset were satisfied with support from their partner, deteriorated in their physical functioning scores (Helgeson et al 2000).

At the end of eight sessions those in the education only group who reported most difficulties at the outset (lack of partner support, lack of physician informational support, low self esteem, low perceived control) showed most benefit in physical functioning scores.

At six months the negative impact of peer discussion groups was no longer evident. However for each indicator of mental functioning overall measures for educational groups were significantly higher than those for peer discussion groups. No overall statistically significant benefits were found for either peer discussion groups or peer discussion combined with education groups, at any stage up to three years.

For the education only group, benefits deteriorated with time but after three years small statistically significant benefits could still be seen in comparison to the control group (Helgeson et al 2001).
Campbell et al (2004) conducted a systematic review of evaluation of peer support programmes from 1980-2002 for people with cancer, provided by peers rather than professionals. They found 21 papers that addressed 17 studies, of which only three were RCTs. Reporting on the non-randomised evaluations the authors note high participant satisfaction, but they also comment that low response rates and lack of feedback from non-respondents and people who dropped out suggests that these positive assessments may be highly biased. All peer support programmes included an element of education or information and both women and men identified informational support as useful. Summarising findings from non randomised studies Campbell et al state that participants had a better understanding of their experience of cancer and were better informed as a result of receiving peer support. Common emotional benefits were hope, encouragement and reassurance.

Of the three RCTs included in Campbell et al’s study none were able to show an improvement in quality of life following engagement in peer support groups and all found varying degrees of adverse outcomes. One of the three RCTs is Helgeson et al, reported above. Another small RCT (n=34) found that an eight week programme resulted in non significant improvements in depression, anxiety and interpersonal problems but worsened life satisfaction, self competency and social competency and a significant reduction in activity levels. The third RCT found that those who received peer support had reduced psychological morbidity after 12 months but also had slightly worse outcomes in anxiety, depression and general health than those who received routine care or nurse support. The authors note that all three RCTs were established by the researchers for the purpose of their study, and may not be representative of peer support in the community⁹.

Finally, and significantly, three other comprehensive and well conducted reviews report mixed findings.

Hoey et al (2008) thoroughly reviewed 44 papers in a systematic review of peer support for people with cancer, including reports of face to face and telephone support provided to individuals and groups, and internet support groups, from 1980 - 2007. Three types of

⁹ Confusingly, Campbell et al conclude that their review ‘revealed consistent and positive benefits from peer support, regardless of the manner in which it was delivered.’ (op cit:14). In a structured abstract of Campbell et al’s review The Database of Abstracts of Reviews of Effects (2010) notes: ‘[Campbell et al]’s conclusions do not reflect the findings from the RCTs as much as they do the findings of the other study designs. This may be justified, in part, by the fact that the interventions studied in the RCTs may not be as representative of real peer support groups as those in the other studies. However, based on the information provided in the review, it is unclear how valid this justification is.’
research papers were included: those reporting descriptively on a single group with no control group; non randomised controls, and RCTs. As well as summarising findings the authors also rated quality of the description and research for each study, categorising each as ‘poor’, ‘fair’ or ‘good’.

Overall, results from the one group descriptive papers found a high level of participant satisfaction and some perceived psychosocial benefits from peer support. The studies suggested that having contact with other people with cancer, by whatever means the contact is delivered, assists people with cancer in social, emotional and practical ways. However, the quality of most papers in this category was rated by Hoey et al as ‘fair’ or ‘poor’ and, as the authors comment, without a control group these findings cannot be more than tentative.

Results from RCTs in Hoey et al’s review were less positive than those from descriptive studies. Four out of ten papers reported an increase in perceived social support among the intervention group, three out of ten found improvements on some psychosocial outcomes during or post-intervention. Three RCTs examined group face to face models and found no significant effect on health-related quality of life or psychological distress. In general, they did not find that participation in peer support programmes led to significant improvement in quality of life nor in coping. The authors did report more optimistically on two RCTs of group Internet programs and one RCT of one to one face to face peer support. The three studies involved are described in more detail below (6.2 & 6.3).

Gottlieb & Wachala (2007) summarised and critically reviewed 44 empirical studies of peer support groups for people with cancer. Unlike the reviews by Cambell et al and Hoybe et al this review included only studies of face to face support groups led, not by peers, but by one or more professionals, including nurses, physicians, social workers, mental health specialists. Similarly to the two previous reviews Gottlieb & Wachala’s findings report high levels of participant satisfaction and mixed but not convincing outcomes.

Woolacott et al (2006) conducted a broad and thorough systematic review of self care support networks (led by peers not professionals) in health and social care, covering a wide range of conditions other than cancer. The authors reviewed 47 papers describing 46 studies. Among their many findings they summarise outcomes for studies addressing long-term conditions (a category in which they include weight control) noting that ‘in long-term conditions...’

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10 Of the 46 studies in Woolacott et al’s review (which excluded peer support for people with cancer) over a quarter (13) addressed obesity or weight problems. The next largest category (nine) was for carers, followed by four studies for diabetes. All other topics (none of which included renal issues) were represented by three studies or less.
conditions 62.5% of comparisons with a no treatment control and 53% of comparisons with baseline found a statistically significant benefit of the self care support network.’ (op cit:14). As they go on to say: ‘[g]iven the relatively poor quality of the majority of the studies reviewed, the high proportion of statistically significant findings would appear to reflect the use of multiple outcome measures rather than be an indication of a strong evidence base’.

5 POTENTIAL EXPLANATIONS AND INTERPRETATIONS OF MIXED FINDINGS

5.1 Common observations across studies
The overview presented by four thorough studies described in the previous section (Campbell et al 2004; Hoey et al 2008; Gottlieb & Wachala 2007; Woolacott et al 2006) offers perspectives and observations that help interpret some of the apparently conflicting findings reported in the peer support literature. Interpretations can, however, only be tentative, one of the key messages from Woolacott et al’s study being the lack of evidence to support generalisations across conditions, or across types of peer support.

5.2 Methodological limitations
There is broad agreement amongst those reviewing peer support that inadequate description and design of interventions and of evaluation limits the confidence that can be placed in findings from most studies.

In the review by Woolacott et al (2006) of 46 studies of health and social care support networks only one was rated as having good study design and internal validity, seven as satisfactory, 16 as poor, and 22 as very poor. All studies relating to conditions covered in this current review were categorised as poor or very poor.

Woolacott et al summarise key methodological flaws as lack of a theoretical framework behind most studies; inadequate programme description; calculation of response rates based on group attendees rather than the eligible population; lack of information on non-participants; and use of instruments and measures that are not validated. Small sample sizes are another challenge, limiting the ability to demonstrate significant outcomes.

As noted above, use of multiple outcome measures increases the likelihood of at least one statistically significant finding, but reduces the trust that can be placed in such findings,
especially when other related outcome measures show incompatible results. Finally, while few studies report adverse outcomes that is partly because few studies look for them.

With so few individual studies of high standard there is limited reliable evidence from which to build understanding or progress.

5.3 Lack of long term follow up

A serious limitation in assessing findings or comparing different approaches to peer support is the varied, but generally short follow up periods for measuring outcomes.

Most studies of peer support test for outcomes only once, immediately after the intervention or, at most, a few weeks later. Occasional studies re-test at six months, but few extend their follow up beyond that time. Helgeson et al (2001) summarise findings by other researchers who re-tested at six months, some discovering increased effect and some finding that earlier outcomes had dissipated.

Helgeson et al (op cit) found adverse effects at six months that dissipated at one year. Another study (Simpson et al 2001) tested for outcomes from a CBT trial at the end of the intervention, after one year, and after two years. Positive outcomes measured immediately post-intervention had dissipated at one year, but were measurable again at two years. Helgeson et al (2001) were unusual in re-testing three years after their intervention (at which time they found no effect from peer support though they did find positive outcomes from education without peer support).

Inconsistent patterns amongst studies that do conduct longer term follow up (with some showing increased effect but more finding diminished effect over time) raise questions about sustainability of positive outcomes from studies that report only post-intervention. Likewise, it is possible that studies reporting adverse or neutral outcomes post-intervention may have demonstrated more positive findings had they re-tested later.

Lack of consensus about accepted and expected periods for follow up also highlights mixed views, across studies, of intended outcomes for peer support. Different outcomes may require follow up at different times.
5.4 Lack of clarity about outcome measures

Gottlieb & Wachala (2005) offer a possible interpretation of discrepant findings in systematic or broad reviews of peer support, where descriptive studies report appreciative positive comments from those involved, but outcomes from quantitative studies are small, non-existent or negative. They suggest that some outcome measures used in quantitative studies are not appropriate for assessing effectiveness of peer support.

This could also explain the apparent paradox reported in individual studies (eg Prins et al 2001, Salzer et al 2010) where participants describe their experience of peer support positively while quantitative scales measuring quality of life, emotional or physical health outcomes for the same participants show no benefit.

Gottlieb & Wachala (2005) observe that studies included in their review that assessed more immediate measures, such as availability of social support, did find a difference between intervention and control groups. They note that few quantitative studies evaluated success of peer support in terms of reduced isolation, increased sense of hope and shared experiences, while these are the outcomes most often mentioned in qualitative studies.

This observation highlights the importance, when planning peer support, of clarifying whether support is the end in itself, or whether peer support is a means to specific health-related ends. If support is an end in itself Gottlieb & Wachala suggest that appropriate measures for success would include behavioural expressions of support, perceived support, positive morale, and, for groups, group cohesion and indicators of group attachment such as regular attendance and active participation.

Where peer support is a means to other ends, Gottlieb & Wachala note the tendency for research studies to use theory or clinical experience to determine outcome measures, rather than consulting with participants to hear outcomes that matter to them. For example, participants may be most interested in gaining specific resources such as more knowledge of the disease and/or new skills for coping with it, while professionals may be interested to know whether acquisition of these resources reduces the incidence of depression or show changes in health-related behaviour.

Gottlieb & Wachala propose that the first step in evaluation should be to measure the extent to which peer support effects change in the behaviours or skills that participants value. The second step would be to assess whether those changes mediated change in the clinical
endpoints of interest. The two-stage approach proposed here would address the observation made by Prins et al (2001) in their study: participant satisfaction and clinical improvement were not correlated and may be independent.

Possible implications to draw from these observations are that failure to demonstrate change using specific quantitative outcome measures do not inevitably imply failure of peer support, but could suggest that (a) there is not necessarily a direct link between the benefits that participants value and the selected outcome measures and/or (b) that the outcome measures are inappropriate or insensitive.

5.5 Individual differences

Peer support is not universally attractive as a context for addressing psychosocial issues. This is demonstrated by limited uptake of invitations to participate in peer support and by dropout rates\textsuperscript{11}. Individual differences in socio-demographics, existing social support networks and specific disease characteristics may influence the appeal of, and also the benefit from peer support to potential participants. Additionally there may be practical hurdles that limit access to peer support.

Research studies are broadly agreed that those who attend peer support groups are not representative of the wider population. Apart from the heavy bias towards women-only groups, even in mixed gender groups there is a strong predominance of women (typically 70-80\% female), participants are generally younger than the at-risk population, middle class, employed and relatively well-educated (Campbell et al 2004, Woolacott et al 2006; Gottlieb & Wachala 2006, Michaeliec 2006, Bui et al 2002).

Slevin et al (1996) surveyed people who had been diagnosed with cancer for a minimum of three months, asking who they would use as providers of emotional support if all sources were freely available. The questionnaire also asked them to rate their satisfaction with any support already used. Of all respondents (n=431) almost three quarters (73\%) said they would most like to use family, and roughly the same percentage chose senior medical staff. Most (80\%) who had already used these sources of support were satisfied. Among choices offered in the questionnaire were support groups, led by peers or a range of health professionals. Less than 30\% of respondents said that they would attend a support group led by any of the options given. Sixty-six percent had already used patients (outside of support groups) for support and only 39\% were satisfied. The authors point out that while it can be

\textsuperscript{11} Gottlieb & Wachala (2006) suggest average dropout rates of 20\% but several studies cited in this report illustrate rates far higher.
helpful for patients to hear the experience of others, it can also be stressful. People have
different coping styles and, for example, for those who cope by maintaining a positive
outlook it is potentially damaging to be with those whose outlook is pessimistic.

By matching men who attended a prostate cancer support group (N=14) with others of
similar age, marital status, socioeconomic status and at a similar stage in the disease who
had not (N=37), McGovern et al (2002) found that only 3% of non-attenders said they would
have attended the group had they known of its existence, 40% said they definitely would not
attend and 57% were not sure. Using an instrument designed to assess five styles of coping
with cancer\textsuperscript{12} men who attended the group were shown to have higher fighting spirit and
higher levels of anxious preoccupation.

Bui et al (2002) studied participation in a support group by using a standardised approach to
invite and actively encourage eligible patients who had been treated for colorectal cancer to
attend an existing support programme\textsuperscript{13}. Of 44 patients who were invited one third (n=14)
expressed interest in the group and two thirds (n=30) said they were not interested.
Analysing patient characteristics several predictors of interest were found, but after
conducting multiple logistic regression just two independent indicators of interest remained:
recollection of encouragement from staff, and level of education. Of the 14 people who
expressed interest only four actually attended the support group. Although gender did not
influence expression of interest, three of the four who attended the group were women.
Though numbers in this study are small and activities offered by the group may have
influenced interest, the high rates of attrition are a telling reminder that group participation is
limited and participants are unlikely to be representative of the wider population.

In a retrospective study Michaelec (2006) aimed to contact all breast cancer survivors
diagnosed in one area of the US from late 1980s to 1999 (n=1528).Of those who could be
contacted 958 were interviewed and completed surveys providing socio-demographic data.
Respondents were asked whether or not they had participated in any breast cancer support
group since their diagnosis. They were also asked questions that measured perceived social
support, life satisfaction, self assessed physical health and perceived overall quality of life.
Of the total sample most had never participated in a breast cancer support group. Those that
had been or currently were members of support groups reported significantly higher levels of
social and overall quality of life than those that did not. Other factors associated with higher

\textsuperscript{12} The Mini-Mental Adjustment to Cancer Scale assesses for: helplessness-hopelessness; anxious
preoccupation; fighting spirit; cognitive avoidance; fatalism.
\textsuperscript{13} As well as providing patient, peer and caregiver support the support programme to which they were invited
included options to engage in yoga, meditation, Reiki and other therapeutic activities.
quality of life were race (being white); age (younger women reported higher levels of social and physical quality of life, older women reported higher psychological quality of life); higher income; being employed; being married or cohabiting; and higher level of education. Those who attended support groups were significantly younger than non-participants, had higher levels of income, higher levels of education, were more often employed and more often married.

Michaelec conducted statistical analysis on the variables to explore the relationship between participation in breast cancer support groups and quality of life and discovered that when socio-demographic variables were controlled for, the effect of support group participation was no longer significant. Similarly, when other support networks, and disease characteristics were controlled for, support group participation no longer played a significant role in determining quality of life\textsuperscript{14}.

Docherty (2004) conducted focus groups with members of cancer support groups to hear from them in what ways they benefited. She reports that the function of the group varied for each member.

The study by Helgeson et al (2000; 2001) is one of few to address the question of who benefits most and least from support groups. Helgeson et al report that women with breast cancer who were satisfied with the level of emotional support they received from their partner deteriorated in physical functioning immediately after attending peer support groups, while those who lacked emotional support from their partners benefited. This suggests that peer support groups may compensate for deficits in naturally occurring networks\textsuperscript{15}.

As well as the influence of personal circumstances, Helgeson et al (2001) suggest that stage of illness may determine the most beneficial style of peer support. They propose that people whose illness is less severe or more controllable might benefit from a problem-focussed intervention that focuses on providing information and enhancing control. People with a less controllable illness or those at later stages of a disease might benefit from an emotion-focused intervention that addresses accommodating the disease (op cit:392).

\textsuperscript{14} Michaelec (2006) points to the weakness in this study, that no differentiation was made between types of breast cancer support groups, nor between levels of engagement for those who participated. It is possible that, had a differentiation been made some effect of participation on QOL may have been found.

\textsuperscript{15} Over time the negative effects were no longer evident and no significant differences, positive or negative, could be demonstrated between group members and the control group.
Given the wide range of approaches to peer support evaluated in the research literature, combined with the commonly unaccounted-for influence of variations in participants’ socio-demographics, stage of disease, coping style, and availability and effectiveness of other support networks, conflicting outcomes become inevitable.

6 APPROACHES TO DELIVERING PEER SUPPORT: IMPACT OF VARIABLES ON OUTCOMES

6.1 Challenge of refining findings
Section 2 of this report proposed six variables which influence the model, or approach by which peer support might be delivered: mode of delivery; format; degree of homogeneity; duration; group leadership and intended outcomes.

Many reviews include a range of peer support models in the same evaluation, making no distinction between, for example, peer led or professionally led groups, or making no distinction between peer support that runs for a short or longer number of sessions. By encompassing a range of models these studies potentially mask variations in outcomes associated with different approaches. The following section explores evidence relating to specific approaches to provision of peer support. At this level of distinction some models of peer support have received limited evaluative attention; often studies are small or lacking in design or descriptive detail, with limited capacity to demonstrate statistically significant findings.

The point should also be reiterated that, just as there is no evidence that it is realistic to generalise findings from one model of peer support to another, Woolacott et al (2006) caution that findings cannot necessarily be generalised from one condition to another. Nevertheless, given the small number of published studies on peer support for renal conditions, the broader literature addressing peer support for long term conditions is explored here for any pointers relating to effectiveness of specific approaches.

6.2 Mode of delivery: face to face; online; telephone

   Face to face
The vast majority of studies address peer support in a face to face context, making it more constructive to consider this variable in combination with others.
Eysenbach et al (2004) conducted a systematic review of computer-based peer to peer communities and electronic support groups used by people to discuss health-related issues remotely. Their remit was wider than that covered by this report, including studies that measured outcomes addressing knowledge, health, psychological or social outcomes, or use of health services, so long as they involved a control group or baseline measure. Out of 45 publications they identified, describing 38 studies, only six related to peer to peer interventions, the remaining 32 were adjuncts to more complex interventions. Of the six peer to peer interventions two were for adolescents, and all but one reported some degree of facilitation with trained health professionals leading the groups as moderators or facilitators. None of the six were RCTs. As the authors say, there is little commercial or professional interest in evaluating virtual peer communities unless they are linked to more complex interventions and/or led by health professionals, so there is little sound evidence about this approach. Overall, Eysenbach et al found that most studies did not demonstrate beneficial outcomes, but they also found no evidence to support concerns over virtual communities harming people.

In the systematic review by Campbell et al (2004) of cancer peer support programmes five studies of internet-based support groups were found. None involved comparison groups but all report satisfaction from at least some participants and appreciation of information and social support. As Campbell et al comment, internet and telephone support may be especially useful for patients with less common conditions, and for people who are homebound, geographically remote or who prefer privacy.

Hoybye et al (2010) conducted a RCT, trialling the effect of access to an internet support group for people who attended a rehabilitation course for cancer survivors. Twenty people at a time, with various cancers, attend each rehabilitation course. Over two years all members of each course were randomly assigned as a control group or an intervention group. All in the intervention groups (n=361) attended a two hour lecture on use of the internet for information on cancer and were invited to participate in an internet peer support group. The internet groups were closed groups, intended as an opportunity to maintain the relationships developed during the course. Overall, of those invited to join the internet group 60% agreed to participate and posted at least two messages. Posting activity peaked in the first three months then dropped off. Of 26 groups that formed internet groups, during the first two months ten posted an average of 2.4 posts per participant; 16 posted an average of 3.5 posts per participant (individual posts ranged from 2-241). Data was collected from
individuals in control and intervention groups at the start, six months and 12 months measuring self reported mood disturbance, adjustment to cancer and self rated health. Psychological well being in control and intervention groups improved over time. Initially the control group showed less improvement but overall, no significant difference was found.

While useful as an indication of participant use of an internet site, the study by Hoybye et al with its closed groups who had already met face to face is not representative of most common experiences of online support groups. Salzer et al (2010) designed a randomised controlled pilot study to assess outcomes for women newly diagnosed with cancer who participated in unmoderated internet peer support groups. Women diagnosed with cancer in the previous 12 months were assigned to a control group (n=51) or an internet group (n=27). The latter were subscribed to an unmoderated but closed discussion group. Demographic data were collected for both groups and data collected on physical and emotional health at the outset then four and 12 months later. The small numbers in the study limited the ability to demonstrate statistical significance, but findings showed small to moderate worse outcomes for those in the internet group than the control group. Authors suggest that negative outcomes could be influenced by the study design, where all participants were newly diagnosed, preventing the opportunity for women to benefit from learning and being supported by long term survivors. From a social comparison perspective this would remove the option for ‘upward comparisons’ which help generate hope. Findings from this study replicate the paradox found in a number of other studies: despite the apparent increase in distress over time indicated by the outcome scales, about 60% of participants said they felt supported by the peer to peer communication and reported high levels of satisfaction with the group.  

Gustafson et al (2001) conducted a RCT with women aged under 60 recently diagnosed with breast cancer (n=246). Women randomly assigned to the intervention group were given six months access to computer-based information, social support and decision-making tools. Measures, among other things, of social support were higher for the intervention group at two months but by five months the control subjects made improvements of their own while the intervention group changed little, leaving less difference, though authors note that those typically underserved (non Caucasian, less educated, uninsured) benefitted most.

In the only other RCT found (Winzelberg et al 2003), women with breast cancer were recruited to participate in a trial of a 12 week internet-based social support group (n=72).

16 The high level of devotion to the group felt by some of the women was demonstrated by the fact that when the trial ended 16 participants created another online discussion group to maintain contact with one another.
Most participants were highly educated. Volunteers were randomly allocated to the intervention group which participated immediately while the control group waited to participate. Multiple measures of depression, stress and coping were conducted pre-intervention and at 12 weeks. The 12 week course involved a moderated support group where each week the moderator introduced a new topic and facilitated discussion. The moderator’s main task was to keep conversation focused on the weekly theme and to encourage members to support one another, and not to offer specialist advice. Over 12 weeks participants logged on to the site an average of 34 times (range 3-122). Outcomes at 12 weeks showed that participants’ scores on depression, perceived stress and cancer-related trauma were all reduced, but there were no significant changes in anxiety or aspects of coping with cancer. Despite the considerable variation in use individuals made of the site, analysis showed that benefits were not related to participation rates. No follow up was conducted beyond 12 weeks.

Concerns raised generally about internet based peer support include the view that online relationships are less valuable than offline ones and can detract from social involvement with friends; questions about quality of information, hoaxes and potential broach of confidentiality (Eysenbach et al 2004). Risks include unsupportive or confrontational on-line discussions which can leave people feeling vulnerable and alone when they most need support. Barriers include the requirement to have access to and familiarity with use of a computer and the internet, and need for ease with written language.

At a practical level however, virtual communities can overcome limitations that seem otherwise unsurpassable, allowing those who are homebound, living in geographically remote areas, or who have relatively unusual conditions to communicate with peers at times of their choosing and over a period as long or short as they wish. Potential participants can retain the degree of privacy they prefer, and can observe or engage in limited communication until they decide whether to participate more fully or to leave.

Conclusions about effectiveness of internet-based peer support are limited by the small number of studies with adequate methodological rigour. The same inadequacies voiced for studies of peer support in general apply to those for online peer support, with added difficulties. Follow up of participants is even more challenging than in face to face groups, and there is no way of tracking outcomes or gauging potential harm for those who drop out. As noted by Eysenbach et al (2004) the range of studies available is not representative of peer support opportunities online, with research mostly focusing on moderated communication between purposively selected participants. As with other modes of peer
support, it appears that appreciation of interaction on the internet does not necessarily lead to measured outcomes, and particularly, not to outcomes that last over time.

Absence of evidence does not mean that virtual communities have no effect. Likewise, absence of evidence of harm from internet support groups does not mean it does not exist. Overall the effect of online support groups on health-related outcomes remains unclear.

**Telephone**

Telephone support is another under-reported area. Dale et al (2008) conducted a systematic review of one to one telephone based peer support, though in each of the seven studies covered by the review calls were initiated by the peer supporter in the context of supporting and promoting health. The range of conditions and topics addressed were wider than those in this report, some having behavioural aims (encouraging breastfeeding, improving diet) as well as those addressing depression or self-efficacy. Analysing the type of peer support provided from the perspective of Dennis's categories of emotional, appraisal and informational support, Dale et al report that studies that included informational support (with or without appraisal support and emotional support) were more effective than those that lacked an informational support component.

A descriptive study in a remote area of Canada trialled up to six teleconference sessions, lasting approximately 90 minutes each, with women with breast cancer as a form of peer support (Curran V and Church J 1998). Total number of participants in any one session ranged from 17-48. A facilitator played a liaison and resource role, but aimed to maintain peer to peer discussion. Respondents (n=17) mostly indicated satisfaction with the sessions, many commenting that it left them feeling ‘not alone’. The area where the trial took place has the most extensive telemedicine and audio teleconferencing system in Canada, and so is atypical in its technical capabilities.

More typically telephone support is used in a one to one context. In a small study (Houts et al 1986) designed to assess the added value of telephone-based peer counselling on coping strategies, patients beginning treatment at a gynaecological oncology centre were assigned to an intervention group (n=14) and a control group (n=18). Experienced social workers who had had cancer themselves acted in the role of peer counsellors. They telephoned each intervention participant prior to hospitalisation and five and ten weeks later, to discuss four main coping strategies that characterise people who have dealt well with cancer. Patients also received an audiotape and notebook explaining application of the coping strategies and a photograph of the counsellor. All participants completed the POMS inventory at the outset.
and six and 12 weeks later but the scales showed no evidence to suggest any difference between the intervention and control group. One plausible explanation proposed by the authors is that all patients at the clinic already received individual attention from two nurses and a social worker who were assigned specifically to these services to offer help with practical needs and emotional support. Patients also had access to three faculty physicians and residents and fellows. While the intervention provided access to an additional type of counselling it was offered in the context of an existing rich support programme, which is not representative of the situation for many other patients. Also, it should be noted that although the POMS scale showed no evidence of benefit, follow up interviews with 11 women from the intervention group found that seven said the telephone counselling had been a great deal of help, two said it was some help and two said it was no help. As a small study it is possible that numbers were too small to demonstrate a positive outcome and/or that, as in other studies (Prins et al 2001; Salzer 2010) patient satisfaction and outcomes measured by POMS are unrelated.

The limited information available on telephone support suggests that it may be appreciated, especially by people who are geographically remote or housebound or bedbound as a means of providing support, though there is no evidence to suggest that it supports any changes beyond an increased sense of support.

6.3 Format: one to one; group.

One to one

In keeping with social comparison theory, one to one peer support generally involves matching the person who will receive support with a supporter who has similar qualities. The specific characteristics to be matched are debatable, but generally treatment modality and/or physical condition are central features. The task of matching requires central coordination, and the implications are that a pool of volunteers is needed, not all of whom might be accessed. There is debate about the level of training that should be provided to individual peer supporters, and about the potential risks or benefits people face when they undertake this role.

The UK-based one to one peer support programme for people with chronic kidney disease (Hughes et al 2004) described earlier (4.3) involved careful matching of peer supporters to those receiving support. If a patient wanted information about a specific treatment option, experience of that treatment would be first priority. Additionally all patients were matched by gender and age, ethnicity and social circumstances. Patients were invited to identify the
experience and background that they would ideally like for their peer supporter. Effective matching requires that the person with this task (in this programme the link nurse) is familiar with the peer supporters and learns enough about the individual patients who want support. No comments from patients were noted in the evaluation about the matching process, which the evaluators interpret as an indication of its effectiveness. In this programme peer supporters participated in four training sessions of about two and a half hours each. At the evaluation 18 out of 20 people interviewed appreciated their single contact with the peer supporter. Most had met face to face and a minority by telephone. The evaluators commented that for those for whom peer support was a positive experience it is notable that perceived gains from one single meeting appear similar to those from longer term membership of a support group. They suggest that part of the value comes from the control users have over when, how and for what purpose they request peer support. Outcomes for those providing support were not evaluated.

Giese-Davis et al (2006) describe an exploratory study with no control group, where women already diagnosed with breast cancer were trained as peer counsellors (n=29) during six separate all day training sessions, then matched with women recently diagnosed with breast cancer (n=39), as peer counsellors or ‘buddies’. Newly diagnosed women were interviewed and given a questionnaire to indicate their preference for the qualities of buddy with whom they would be matched. Most ranked common diagnosis, treatment protocol or a specific treatment concern as the most important criteria. Contact between peer and peer supporter could be face to face, by telephone or internet; telephone was most frequently used. Contact could be once to four times a week, and was initiated most often by peer supporters. The programme intended peer counselling to continue for six months; ten of the 39 women being counselled were matched twice and two were matched three times over that period. Reasons for change included change in personal circumstances, desire for closer match on treatment, personality, and change in medical status of the peer counsellor. Outcome measures of emotional well being and cancer self-efficacy increased for those being counselled over the six months, but there were no changes in social well being or depression. Without a control group it is not possible to know how these outcomes compare with changes that could be expected with passage of time. Contrary to expectations those giving support did not show beneficial changes over time, but also, did not deteriorate.

The following study (Brunier et al 2002) also found no quantitative evidence of either improvement or deterioration in psychological well being amongst one to one peer support volunteers, however qualitative responses indicated beneficial outcomes for the peer supporters.
In one of the few reported evaluations addressing renal peer support Brunier et al (2002) report that while a few studies, in other areas, have found that peer counsellors experience rewards and benefits from their volunteer role, other literature points to the risk of negative experiences for volunteers. In this study people with end stage renal failure, or their family members, who had completed the Canadian Kidney Foundation training programme for peer support volunteers were invited to participate in an evaluation. Thirty-six agreed and 31 completed the twelve month study, four of whom were family members. Demographic and qualitative data was collected from peer support volunteers at the outset and their psychological well being was assessed using the Mental Health Inventory. Volunteers were found to be younger than average renal replacement therapy patients (average age of volunteers was 45 compared with 60 for new patients starting dialysis in Canada), and they had higher educational qualifications than the standard population. Qualitative data was collected again four, eight and 12 months later and the Mental Health Inventory was re-administered.

Over the year-long study period volunteers were matched to patients by the peer support coordinators. Each peer support volunteer saw on average five patients, with an individual range from 0-17. Two people, both family members, did not counsel anyone. Data collected using the Mental Health Inventory showed that average scores remained stable over the year. Qualitative data showed that volunteers had developed strong and supportive relationships with each other. Several also said that they had come to terms with their own illness through becoming a peer counsellor, that they had benefited from counselling others, and that they found the role satisfying and fulfilling. A limitation of the study was that volunteers were not assessed prior to attending the training programme, so it is not possible to know to whether any of the qualitative benefits described were attributable to the training or the subsequent role of volunteer.

Moving back to consider one to one counselling from the position of the person receiving counselling, Rankin et al (2004) evaluated uptake and acceptability of a peer support programme in Australia. The Australian Breast Cancer Support Service (BCSS) offers practical and emotional support to women recently diagnosed with breast cancer through one to one visits from peer supporters who have themselves previously experienced the disease. Women mostly learn about the programme from a clinician or health professional

17 The authors of this study suggest that instruments that measure psychological well being may be inadequate to capture improvements over time.
who contacts the service to arrange a volunteer visit. Volunteers receive initial training and attend regular courses organised by local coordinators.

Women in Australia diagnosed with early breast cancer over a six month period were identified and contacted by their doctor, if their doctor agreed to participate. A total of 544 participated by completing a telephone interview six to 12 months after their diagnosis. The telephone survey collected demographic data and asked questions about information and support received during the women’s diagnosis and treatment. Amongst the support questions was a list of possible sources of support, with BCSS listed as one of the options. Just over one third (36%) of participants indicated that they had used BCSS since their diagnosis, making BCSS fifth highest amongst listed sources of support (top four were: surgeon – 58%; general practitioner - 53%; some other group or person – 53%; oncologist 37%). Most common reasons given by the remaining two thirds of participants (64%) for not using BCSS were that they already had enough support from family and friends (43%); that they did not know about the service (23%); and that they did not think it would be useful (20%). Those who had used the service reported the following benefits: talking to a woman with similar experiences (53%); emotional support (15%); practical advice (12%); information (10%). The great majority (85%) who had used the service said they would definitely recommend it to other women and another 10% said they probably would recommend it.

Unusually, demographic analysis of those who did and did not use BCSS showed no significant differences in age, education, marital status, rural or urban dwelling, or public or private health insurance. Those discharged from hospital within 48 hours were least likely to use the service, suggesting the key difference was adequate time to receive information from a clinician or health professional, or to contact the service and receive a visit.

In an earlier evaluation of the BCSS (Dunn et al 1999) women who had used the service (n=233) responded to a survey that aimed to identify features of the volunteers’ visits that were most helpful to women with breast cancer. Timing of the visit proved to be a critical factor. For women in hospital the period soon after the operation is a time when information and support needs are highest. Matching the volunteer to the patient was also important, though, contrary to expectations, age similarity was seen as a less important factor than perceived similarity in way of life and beliefs.

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18 Support was defined as ‘someone to talk with about the problems or difficulties you were experiencing or about personal issues, such as emotional or relationship difficulties, how you and your family were coping and so on.’
Geiger et al (2000) evaluated a one to one programme in N America and also demonstrated satisfaction amongst those using the service. The Breast Buddy Breast Care Program (BBBCP) was established to provide support and information about treatment options to women newly diagnosed with breast cancer. Aims of the programme are improved patient satisfaction.

The BBBCP was established at two medical centres. A registered nurse was appointed as programme coordinator at each site to act as an advocate for the programme, to coordinate it and to recruit, train and supervise patient mentors. The coordinator met all patients at the time of diagnosis to introduce the BBBCP and to offer the informational and support components of the programme. Information included books, brochures and access to a lending library. Support was offered through patient mentors who were women with a history of breast cancer who had completed at least 16 hours training and were willing to commit a minimum of one year for each person who they ‘buddied’. Mentors were encouraged to contact their buddy at least once each week and to file regular contact reports with the programme coordinator. They were matched to the patient buddy by the programme coordinator, according to factors that included similar breast cancer diagnosis, spiritual beliefs and geographical proximity. The programme coordinator was available for consultation at any time during the course of the treatment at the request of the patient, physician or mentor.

Of all women offered the programme, about 40% requested a patient mentor at the time of diagnosis, 20% requested a mentor at the time of chemotherapy, and about 75% used the lending library at least once.

Avoiding the methodological criticism levelled at most evaluations, this study invited all women who received a breast cancer diagnosis at the two implementation sites over a six month period to participate in the evaluation, regardless of their level of participation in the programme. Those who agreed to participate \((n=111)\) were matched by month of diagnosis with a sample of women \((n=277)\) whose disease was diagnosed at non-intervention sites, as a control. Both groups of women were surveyed four months after their diagnosis to measure their satisfaction with breast cancer care, using a specifically developed instrument. The survey asked questions about satisfaction with aspects of breast cancer and non-breast cancer care, based on the hypothesis that because the intervention targeted only breast cancer services, satisfaction would improve in only those aspects in the intervention group.
Findings demonstrated that women at intervention sites showed statistically higher satisfaction ratings for breast cancer care (71% compared with 56% were very satisfied) but, in keeping with the hypothesis, no significant differences in satisfaction were found with diagnostic and surgical care.

This study is one of few to report financial costs. Estimated at US$100,000 (in 2000) for two intervention sites, most of the outlay covered salary for programme coordinators, with some costs for informational materials. Ongoing costs include training for patient mentors though it was assumed that programme coordinators’ costs should reduce once the programme was well established.

Finally, Hoey et al (2008) refer to a RCT of a one to one support programme where men with prostate cancer were matched with a long term survivor of the same disease and met eight times over eight weeks. While depression scores for the intervention group dropped at four weeks they showed no difference with the control group at eight weeks, though self efficacy did increase.

To summarise, while there is a reported risk of over burdening peer supporters who provide one to one support, no evidence of harm is noted in studies covered by this review, and peer supporters comment positively on the experience. One to one support appears to meet perceived needs for informational and emotional support, though little evidence is available of more indirect benefits.

**Groups**

The majority of studies evaluating peer support do so within a group context. Appreciation is frequently voiced by participants and quantitative beneficial outcomes of various types have been found. Some adverse effects have also been reported, and many studies show no significant difference between intervention and control groups. There is no generic evidence suggesting that group support is effective per se; potential value of peer support groups is most usefully considered in the context of mode of delivery and in combination with the other variables discussed below.
6.4 Homogeneity/specificity: gender, condition

Gender-specific groups

The literature on peer support for people with cancer colours the frequency of gender specific groups, with a heavy bias towards peer support for women with breast cancer\(^{19}\). Nevertheless, gender-specific diseases apart, studies of peer support exclusively for women are more common than those for men, and most studies of mixed gender peer support report a predominance of female participants. Woolacott et al (2006) in their study that excludes cancer-related peer support note that of 46 studies two were exclusively for men; seven exclusively for women; seven included 30-40% women; and the remaining 30 included over 60% women.

None of the studies included in the current review considered the merits of single versus mixed sex peer support, though reference is often made to gendered styles of seeking support. Men are described as taking a more instrumental or teacher-audience approach to self-help. The initial reason for men to engage in peer support is claimed to be a search for information about their illness, rather than the search for emotional support that is said to characterise peer support for women (Clark 2000; Adamsen 2001; McGovern et al 2002).

Sullivan (2003) studied communication posted on two gender specific online support groups, one for women with ovarian problems and the other for men with prostate problems. Her findings match the stereotypes closely. Communication on the male site is described as ‘report talk’, where men post messages that establish and defend their personal status and exhibit knowledge and ability, but tend to avoid discussion of feelings or problems. Support on this site appeared to be experienced through sharing medical information. Few messages were primarily emotionally expressive or personally revealing, other than a discussion about sex. Most postings requested and shared medical information using complex medical jargon.

By contrast Sullivan described messages posted on the women’s site as tending to set an optimistic tone, offering emotional support in the form of compliments, expressions of gratitude, sending positive good wishes, hopes and prayers. There was much emphasis on empathic understanding and sharing of details with personal disclosures and anecdotes.

\(^{19}\) Out of 17 studies in the review by Campbell et al (2004) 9 addressed breast cancer; of 44 studies reviewed by Gottlieb & Wachala (2008) 16 were for women with breast cancer; of 44 papers reviewed by Hoey et al (2008) 31 were for women with breast cancer. It is widely reported that women outnumber men in peer support groups for people with cancer in a ratio of 4:1 (McGovern et al 2002; Clark 2000).
Sullivan notes that users on both sites appeared to find the interchange beneficial, but clearly, this says nothing of those who were not attracted to these communication styles and opted not to engage or who stopped using the sites. In any group norms are constructed by expectations of group members and modelled by influential members. It is possible that on either site some members may have preferred a more diverse range of communication styles and topics, but been checked by group norms. While this may be beneficial for some, providing a means of communication that meets their needs, for others it may be limiting.

Despite the characterisation, in some studies, of women’s groups as primarily focused on emotional sharing, other studies report that peer support with an educational or informational focus is more effective than support that focuses purely on emotional sharing in delivering psychosocial benefits for women, as well as for men (Helgeson et al 2001, Dale 2008). Undeniably some women and men may prefer single gender groups, but it is equally likely that many people will benefit from the potentially wider range of communication styles, content and interests in a mixed gender group.

**Condition-specific groups**

Dennis (2003) states that research has demonstrated that the more homogenous peer relationships are, the more likely it is that support will lead to understanding, empathy and mutual help, via the mechanism of mutual identification, shared experience and sense of belonging.

Social comparison theory supports the concept of mutual identification, and is borne out by commonly reported views from participants of peer support that only those in a similar situation can appreciate and understand their experience, and accounts of the benefits gained from realising that others in the same situation face similar problems.

Along with mutual identification the other component of social comparison theory is the opportunity for upward, downward or lateral comparisons. It is said that most people select the level of comparison that allows them to view life more positively.

In a study cited above (5.2) by Salzer et al (2010) where women newly diagnosed with breast cancer communicated on a closed website, their worsening scores for psychological distress and quality of life in comparison with a control group who did not use website was potentially accounted for by the fact that all women on the site were newly diagnosed, not allowing them the opportunity to make ‘upward comparisons’ with women who were long term survivors.
Groups vary in the extent to which they are condition-specific, or specific to a particular stage in an illness or disease. In keeping with the proposition by Salzer et al that a lack of diversity on their website supported negative outcomes, Curran & Church (1998), describing group teleconferences for women with breast cancer, claim that a good mix of newly diagnosed patients and long term survivors is needed. They claim that the success of self help support groups depends on having members in the group who are at different stages of the disease. More recently diagnosed individuals can share anxieties with the longer term survivors who in return can offer support and hope.

From a theoretical perspective this proposal is also supported by the ‘helper therapy’ approach, and evidenced by reported comments from peer group members who feel that they benefit from providing support to others (Ahlberg & Nordner 2006).

Studies where participants who join a support group in a better position psychologically show an initial deterioration, while those in greater need improve (Messmer Uccelli et al 2004; Helgeson et al 2000) prompt questions about the overall benefits or appropriateness of this mixed approach. To avoid potential damage to those in a better position Helgeson et al (2000) ask whether participation in peer groups should be limited to those who lack support in their existing relationships. Yet as the same authors point out, a peer support group composed only of people who lack support may not be able to create the same atmosphere of validation and mutual support as one with more mixed levels of satisfaction and pre-existing support.

The risk that participants who feel stronger psychologically suffer, whether from giving more than they are able or from developing a more downbeat perspective on their personal circumstances after hearing others’ views, may be somewhat mitigated in groups with effective facilitators. Neither study cited above demonstrated large or lasting deterioration amongst participants who started the group feeling more positive. Yet the risk of overburdening or depressing the more well participants remains a concern, particularly in self led groups. Likewise, the potential for too homogenous a group to find few opportunities for observing and finding hope and support is another risk to be avoided.

It is challenging to weigh these potential risks against the positive views expressed by participants of support groups, but important to recall that, valuable as they are, views from those who remain in support groups may not be representative of those who do not.
6.5 Duration: number of meetings and time over which they are run

There has been little exploration into whether support is more important at particular stages of a disease and what duration of support is needed to be effective (Campbell et al 2004).

While most reported studies run for three months or less, several authors observe that the more effective interventions are those that extend over a longer duration (Gottlieb & Wachala 2006; Hoey 2008). Helgeson et al (2001), in a critique of their own study acknowledge the likelihood that provision of emotional support by peers needs far longer than eight weeks for benefits to be realised. Gottlieb & Wachala (2006) suggest that interventions lasting between six to 12 months may be most beneficial.

Woolacott et al (2006) comment that the varied range of follow-up periods amongst studies probably conceals any association between duration of intervention and success rate, as well as concealing any association between time of follow up and success rate.

Helgeson et al (2001) suggest that timing of support should be determined by the stage of illness, and that different styles of peer support become more beneficial at different stages. Diagnosis is a critical time and so are key decision stages.

6.6 Group leadership: peer or professional

Peer leaders

There is little evidence available on entirely peer led support. Woolacott et al (2006) in their review of 46 studies noted only one intervention with no professional input at all, and this, as with most other peer led studies in the Woolacott et al review, was a programme addressing weight loss. In addition to input from professionals, most support networks reported in the literature are established by researchers, leaving questions unanswered about the benefits, risks and functioning of genuinely peer led support.

Despite the lack of studies on entirely peer led support, there are strong supporters of the approach in the literature. Dennis (2003) emphasises that a peer leader shares salient target population similarities and has specific knowledge that is concrete, pragmatic and derived from personal experience rather than formal training. She, and other authors state that participants value differently information heard from peers who have experienced rather than learned facts and opinions.
It is agreed that some training is necessary to help potential leaders develop skills that enable effective use of experiential knowledge and to clarify aims of the intervention, but there are no guidelines or agreement about the extent of training needed.

Dennis claims that caution is needed to avoid peers becoming para-professionals with corresponding loss of ‘peerness’. ‘When peers are professionalised their talents and accountability to the target population are shifted to the health-care system, diminishing their mutual identification, credibility and commonality with clients’ (Dennis op cit:328).

*Professional leaders*

The survey by Slevin et al (1996) asking 431 patients with cancer from whom they would most like to access support found that, of those who would use peer support, the majority prefer groups led by professionals rather than by peers.

Most descriptive studies of group support, whether face to face or virtual, describe a role for one or more professional leaders (McGovern et al 2002; Adamsen 2001, Helgeson 1999).

Two main reasons are given for professional leadership of support groups. One is to ensure accuracy of information. Group members often seek information about their condition, about treatment options, and about resources, and it is important that information they receive is reliable and objective.

The second is that professional skills are needed to nurture a positive group culture, manage interactions and avoid or address potential risks. Even where the leader’s main role is not to provide information but to promote peer to peer communication, their input is described as significant (Clark et al 2000).

Ahlberg & Nordner (2006) describe how women in their support group valued the group leaders, an oncology nurse specialist and a psychotherapist, who helped foster support among the members. Women who attended the group said they felt that the group leaders affirmed every member of the group, were skilled at asking questions, gave good advice and left all group members feeling cared for. Gottleib & Wachala (2006) suggest that part of the role of a facilitator is to actively ensure that the group climate remains moderately calm, indicating to participants that they can moderate their distress. Without this moderating influence there may be little opportunity for social comparison to operate positively.
In the absence of adequate evidence for entirely peer led support groups, and conscious of the risks identified for group support, professionally led groups appear the more prudent approach.

6.7 Intended outcomes

Section 3.2 of this report outlined outcome areas most frequently reported in studies of peer support, summarised under headings of social support; emotional outcomes (including levels of mood disturbance, depression, anxiety, hope, adjustment to illness); self-efficacy; knowledge and understanding of disease; health behaviour; health outcomes; use of health service resources; and health-related quality of life.

Qualitative studies generally report outcomes perceived by participants, describing the influence of participation in peer support on one or more of the following areas: perceived levels of social support, emotions, self-efficacy, understanding of their disease and increased ability to make informed decisions. Most comments are positive.

Quantitative scales assess a wider range of outcomes and show more varied results, not just across a range of studies, but confusingly, within studies. The paradox, referred to earlier (5.4) where participants comment positively on their experience of peer support, but when measured on some outcome scales indicate no benefits or show deterioration, prompts questions about (a) validity of qualitative comments (b) validity of some quantitative measures or (c) appropriateness of outcome measures. There may be no single culprit, any or all three may be faulty.

Addressing first qualitative comments, as noted earlier, unless views are heard from those who leave peer support interventions before the intended number of sessions is complete, comments from those who reach the end cannot be seen as representative, inevitably being biased towards the most appreciative. Questions can also be asked about the validity of positive comments when given in a focus group setting, where it may be challenging to offer critical or even neutral comments or to report adverse effects.

Questions about validity of quantitative measures are specific to individual tools. It is easiest to have confidence in well known and well validated tools, yet few measures are entirely free of debate about validity, and measures for some outcome areas are not well developed or may be seen to need adaptation to specific circumstances (eg social support and self-
efficacy). A case can be made that at least some of the tools used to measure change in emotions or self-efficacy are simply not sensitive enough to give meaningful information.

The third area of questioning, the appropriateness of some outcome measures, is the most complex. Gottlieb & Wachala (2005) challenge the basis on which outcome measures in many studies are selected, claiming that theory or the researchers’ clinical experience often determines the measures used. Application of multiple outcome tools does not mitigate the charge of inappropriateness but multiplies it.

The variety of outcome measures used to assess the effectiveness of peer support highlights the range of changes peer support is believed to influence, some based on explicit theory-based logic, others more implicit or unreasoned.

Revisiting the list of potential outcome areas, each varies in levels of immediacy and direct or indirect relationship to the content of the intervention. As Gottlieb & Wachala (op cit) ask: is peer support seen as an end in itself, or a route to other health-related ends? An increased sense of social support, increased access to information, or increased satisfaction with services are realistic, direct outcomes to anticipate from peer support, and are frequently reported in qualitative studies, and sometimes in quantitative studies (Geiger et al 2000; Rankin et al 2004). Reduced levels of depression or more positive mood states are a less direct outcome, while improvements in physical health and reduced use of health service resources are many steps away, not only in chronological time, but in the chain of events where change in one area may or may not mediate change in another.

It is misleading to consider success or failure to demonstrate change in an area of more direct impact (eg social support, increased access to information, or satisfaction with services) in the same category as success or failure in a more remote one (eg depression or physical health).

Few studies make explicit the programme logic by which peer support will achieve the intended outcomes, yet only by demonstrating success in the first area of change in the intended progression can likelihood of success further in the chain be logically anticipated. Additionally, many studies measure for outcomes that appear ambitious after a comparatively small intervention. Failure to demonstrate success may reflect poor programme logic, inadequate dose, and/or inappropriate choice of measurement tools.
Another compounding factor is lack of clarity about the duration, after an intervention, that any outcomes should persist. Few studies conduct follow up beyond 12 months. Little is written about what constitutes success; whether, for example, an intervention that produces outcomes that dissipate within six months or 12 months should be considered effective or not.

Summarising, it is logical that the first outcomes to be measured should be those most directly related to peer support, using valid approaches to assess changes in emotional, informational and appraisal support. Without achieving change in one or more of these areas there would appear to be no basis for considering the intervention a success. Acknowledging that the views of those completing an intervention are not representative of those who drop out or never participated, valid evidence of change in these areas is an initial, if partial success.

If more indirect goals are intended (eg changes in depression, physical health, quality of life), as well as needing confidence in the measurement tools, a logical case should exist outlining how the change in support will mediate changes in the other intended outcome areas. Without both of these provisos failure to demonstrate success may reflect poor evaluative design, and/or may indicate that peer support is not an effective tool for meeting the goal.

Arguably, much of the apparent failure of peer support is due to confused and confusing application and reporting of outcome measures, but without clarity about intended outcomes, confidence in validity of outcome measures, and agreement about realistic periods for follow up, there is no agreed way forward to demonstrate success.

## 7 REALITIES, RISKS AND BENEFITS

### 7.1 Realities
Taking a realistic view, two related but separate questions arise: how closely do research findings about peer support match the real world, and how significant are these findings in the real world. There is a third question: what are the costs?

Looking first at the relationship between research and reality, as noted above, most research into peer support has focused on professionally led groups, with far less known about the process, risks and benefits of entirely peer led groups (Ussher 2006, Michaelac 2006).
Findings are often generalised across both categories, though there is not sufficient evidence to justify extrapolation.

Formation of peer support for research purposes is often unrepresentative of reality, with models frequently designed and initiated by researchers. Participants are sometimes specially invited, or allocated to groups by random assignment based on demographics or disease-based status, rather than motivation to seek support. Whether or how this influences the group functioning and outcomes, and how it may differ from voluntary participation in groups is unknown (Michaelec 2006). Hoey et al (2008) suggest that when psychosocial interventions are delivered to those most in need the positive impact of the intervention is greater, suggesting that some research designs may understate potential value.

Finally, on this question, research-based trials of peer support run the risk of exploring efficacy rather than effectiveness. Studies operated from university departments or funded by adequate research grants are often better placed to attract optimal professional input than the same model run in normal circumstances. Successful outcomes achieved in a research setting should be trialled in a community setting before effectiveness can be demonstrated (Gottlieb & Wachala 2007).

Considering the second question, relevance or place of peer support in real life, two areas of evidence must be borne in mind. One is that, even when well informed about the options for peer support fewer than half of the eligible population express interest at a particular point in time and generally far fewer actually participate (Slevin 1996; McGovern et al 2002; Bui et al 2002, Curran & Church 1998, Geiger et al 2000). In itself this may not matter. If the main reason peer support is effective is because it meets gaps for emotional or informational support in naturally occurring networks (Helgeson et al 2000) then those who do not access available programmes may not need them.

The second area of evidence, however, suggests that not only is peer support only accessed by a proportion of the population, it appears to only meet the needs of a specific section of the population. Participants in peer support tend to be younger, better educated, more likely to be married, white, middle class and employed (Michaelec 2006; Campbell et al 2004, Woolacott et al 2006). Other studies suggest that peer support appeals to those with particular coping strategies (McGovern et al 2002). These findings suggest that however

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20 The evaluation of a one to one peer support programme for women with breast cancer (Rankin et al 2004) is the only study in this review that reports uptake by more than 50% of the eligible population and where participants’ demographic status was not an influential factor.
effective and available peer support becomes there may be sections of the eligible population to whom it will not appeal.

Practical considerations of financial and other costs are rarely reported. Geiger et al (2000) report the cost (US $100,000 in 2000) for establishing a one to one peer support programme in two sites. Campbell et al (2004) raise practical considerations for voluntary groups who decide to establish peer led activities. Organising and maintaining peer support inevitably requires fundraising, advocacy and outreach. As they warn, the activities involved may erode the benefits of emotional and informational support.

7.2 Risks
As noted by Woolacott et al, after an extensive review of 46 studies: ‘[t]here appears to be little indication of adverse effects of self care networks, however, this may be a reflection of the lack of specific investigation of adverse effects’ (Woolacott et al 2006:xvi)

Negative outcomes demonstrated in the studies above (4.3) were small and/or apparently short-lived (Messmer Uccelli et al 2004; Helgeson et al 2001) yet there is general agreement that little attention has been paid to negative impacts (Dennis 2003). Those who drop out of peer support are rarely followed up and little work is done to explore unintended consequences (Gottlieb & Wachala 2007).

Campbell et al (2004) report difficulties in support groups, including member conflicts, upsetting discussions and difficulty dealing with member death. Docherty (2004) lists other challenges identified by support group leaders including varied length of membership, irregular attendance, members feeling threatened by the open communication that is encouraged, medical progression of participants, experience of loss when members leave, and potential for member dependency.

Gottlieb & Wachala (2007) point to the risk that discussions may draw attention to problems not previously considered, or not considered as problems, leading to participants feeling themselves to be more distressed than they previously thought.

Returning to the main theoretical models that underpin peer support (3.3) there is little discussion in the literature about the potential for social comparison theory to work in a negative direction by reinforcing negative thoughts or patterns, or by diminishing feelings of self efficacy. Equally, considering stress and coping theory, which claims that perceived
availability of coping resources provides a buffer against stress, as Gottlieb & Wachala (2007) point out, support is by no means a guaranteed product of a group's composition and interaction. Thirdly, while the helper therapy principle suggests that helping others supports positive outcomes, Dennis (2003) cautions against the risk of stress from over-involvement in other peers, exploitation or over-burdening.

Experienced facilitators can limit, but not entirely avoid impact of these risks. Fewer risks have been reported associated with internet-based support or one to one support, though less research has been done in these areas.

7.3 Benefits

There is much commonality in the reported direct benefits of peer support. Engagement with peers at best leads to development of a sense of mutuality and cohesion, empathy and non-judgemental acceptance. Identification with others in the same situation can bring feelings of normality, belonging, and being cared for. A sense of connectedness with others can result in increased confidence, hope and a change in position from victim to agent. Information gained from peers is especially valued, being based on personal experience. Individuals have the opportunity to witness and model positive coping strategies from their peers. These benefits can lead to increased ability to cope and to relate to health professionals in a more empowered manner. (Docherty 2004; Ussher et al 2006; Dennis 2003; Woolacott et al 2006).

As noted above (6.7), acknowledging that views from participants are probably not representative of those who do not participate or who drop out, undeniably some people experience outcomes that they value from peer support.

Lack of clarity or diverse views about what constitutes evidence of success or worthwhile benefits from peer support leaves open the question of whether the immediate benefits experienced by some participants are adequate justification to implement or maintain interventions of this type. If more indirect benefits (e.g. measureable change in emotional health, physical health or in health-related quality of life) are seen as either the purpose, or the proof of positive peer support there is insufficient evidence to make the case for peer support, whatever model is applied.

One of the concluding statements in Woolacott's extensive review of peer support networks in health and social care is worth stating verbatim: ‘... overall the evidence of a beneficial
effect of self care support networks as a generic intervention is very weak. Although there are a considerable number of studies, a high proportion of which report significant benefits compared to a no treatment control or to baseline, this does not constitute a strong evidence base: the majority of the studies, even the RCTs, are of poor quality. Most studies used multiple outcome measures and the interventions themselves varied considerably. The more reliable findings from comparisons with control in the better quality studies suggest that some self care support networks in certain settings can be beneficial. However, as these studies comprised a trial of Weight Watchers, three trials of carers in Hong Kong and one of a TB Club in Ethiopia, the generalisability of the findings to the UK healthcare environment is at best limited’. (Woolacott et al 2006:xvi)

In the absence of sound evidence of statistically significant or lasting changes, the potential for achieving the reported benefits described by some participants must be weighed against potential risks, the proportion of the target population who will benefit, and the outlays.

8 REFERENCES


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