

Mutual aid groups in psychiatry and substance misuse

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Background:

Mutuality is a feature of many 'self-help groups' for people with mental health and/or substance misuse needs. These groups are diverse in terms of membership, aims, organisation and resources. Collectively, in terms of the pathways for seeking help, support, social capital or simply validation as people, mutual aid groups figure at some time in the life story of many psychiatric and/or substance misuse patients. From the viewpoint of clinical services, relations with such groups range from formal collaboration, through incidental shared care, via indifference, to incomprehension, suspicion, or even hostility. How should mental health and substance misuse clinicians relate to this informal care sector, in practice?

Aims:

To synthesise knowledge about three aspects of the relationship between psychiatric/substance misuse services and mutual aid groups:

- profile groups' engagement of people with mental health and/or substance misuse needs at all stages of vulnerability, illness or recovery;
- characterise patterns of health benefit or harm to patients, where such outcome evidence exists;
- identify features of mutual aid groups that distinguish them from clinical services.

Method:

A search of both published and unpublished literature with a focus on reports of psychiatric and substance misuse referral routes and outcomes, compiled for meta-synthesis.

Results:

Negative outcomes were found occasionally, but in general mutual aid group membership was repeatedly associated with positive benefits.

Conclusions:

Greater awareness of this resource for mental health and substance misuse fields could enhance practice.

Keywords: dual diagnosis; mutual aid groups; psychiatry; substance misuse

*It matters not how straight the gate.
How charged with punishments the scroll
I am the master of my fate
I am the captain of my soul.*

William Ernest Henley (1875)

Introduction

The potential role of 'self-help groups' within the wider mental health systems figures little in conventional psychiatric and addiction training. For example, in the 2432 pages of the *New Oxford Textbook of Psychiatry*, less than a page and a half are devoted to self-help groups (Flynn, 2000), with no references to indicate any evidence base for their value. The main British review of 'self-help' was conducted for the Department of Health's policy research programme and focused on individuals' use of printed, taped or computer-generated self-management materials. In relation to groups, the review reported that 'studies had virtually nothing to say about the work of self-help groups, who attends them or their relationship with statutory services' (National Institute for Mental Health England (NIHME), 2003).

This review aims to examine the concept of self-help groups, their effectiveness in complementing other treatment modalities and their role in helping clients with mental health and/or substance misuse needs. To focus on the benefits and risks of mutual support provided within such groups, we employ the term used by many group members themselves: mutual aid groups. In analysing and interpreting research evidence, the authors have been influenced by previous British studies of social capital (Health Education Authority (HEA), 1999), especially debates on reciprocal relationships, trust and group resilience underpinning mental 'well-being' (Royal Society, 2003).

This review was originally instigated as a result of a consultation process on mental health and social exclusion in England (Social Exclusion Unit, 2003), including concerns about 'the role of social networks and local communities' in relation to psychiatric services. Equally, the call for better prospects to increase the availability of self-management and of a primary care shift to managing chronic diseases in the NHS made such an enquiry a pertinent one (Wagner, 2000). There has been a gap in the evidence around mental health and substance misuse groups within the UK (Richards, 2004).

Mutual aid groups are as old as human history (Kropotkin, 1904). They would seem to answer aspirations of the World Health Organization (WHO) Declaration of Alma Ata (1978): 'Just as governments must provide adequate health and social measures' the people of any country have 'the right and duty to participate individually or collectively in the planning and implementation of their health care' (Section IV). However, in the UK, previous authors have described two 'separate worlds' of the self-help group, and of professionals (Wilson, 1994a).

Historically, there has been a US dominance of the literature, for example in relation to Alcoholics Anonymous (AA, 2001), the American Self-Help Clearinghouse¹ and the Self Help And Mutual Aid Research Network.² Kyrouz and Humphreys (2003) published an overview of US research on outcomes and more recently, Munn-Giddings and Borkman (2005) analysed individual and group gains from a variety of self-help groups. In relation to mutual aid, American history has reached an interesting point, where the President (G.W. Bush) is strongly opposed to a national health service, but praises self-help for alcoholism. To guide psychiatry and substance misuse fields in the NHS, we searched especially for outcomes for groups within the UK context.

Preliminary scoping of the research literature

Alcoholics Anonymous (AA, 2003a) estimate that out of 1.2 million members in the US and Canada, 48% have been sober more than five years. The modest positive association between AA attendance and abstinence appears to apply to all AA members regardless of their ethnic backgrounds (Tonigan, Connors, & Millar, 1998). The US experience is summarised by the National Institute on Drug Abuse (1999): 'Participation in self-help support programs during and following treatment often is helpful in maintaining abstinence' and 'Self-help groups can complement and extend the effects of professional treatment'.

A high proportion of patients in some US clinical services have already engaged in a self-help group, for example, out of the 642 patients in Westermeyer et al. (2001), 78% 'had tried one or more types of self-help, with a mean of 2.7 methods per patient'. The personality dimension of 'persistence' predicts attendance at group meetings (Janowsky et al., 1999), but

not age, gender or the severity of either depression or dependence. There have been many attempts by American professionals to characterise 'successful' groups (Rootes & Aanes, 1992). From the lay carer perspective of 202 members in the Alliance for the Mentally Ill of Pennsylvania (Citron, Solomon, & Draine, 1999), longer-term participation is associated with more benefit from belonging to a group. While some mutual aid groups have a short life, others survive over long periods, and Wituk et al. (2002) contrasted features of 94 'recently disbanded' groups with 245 active groups. A ground-breaking Canadian survey of 75 members active in 'survivor-run businesses' (Trainor & Tremblay, 1992) found mutual aid substantially reduced their need for hospital admissions and other clinical services. For 10 paired community mental health services and self-help groups, in the same locality, Segal, Hardiman, and Hodges (2002) characterised their combined 673 service users. An international study by Borkman et al. (2005) uses similar interviews for group leaders and support staff across mental health self-help organisations in the US, Sweden and the UK. They describe both common and divergent aspects of the evolution of user-led groups, within different mental health systems.

In general, most of the outcomes data originate in the US and robust reports of positive outcomes are predominantly around alcohol use disorders (Lemke & Moos, 2003; Vaillant, 2003). Nearly all outcomes studies used cohort, case study or retrospective (satisfaction) survey designs: random allocation within controlled trials seems not to be consistent with typical self-selecting groups. However, in a few US experiments, professionals have made a random allocation of some patients to aftercare involving community groups. For example, Kaufmann's (1995) Randomised Control Trial (RCT) of vocational rehabilitation followed up people with severe mental illness for one year, reporting an improvement in the group allocated to 'mutual peer support'. In evaluating 'self-esteem' groups for patients with schizophrenia based on 'freedom of choice, independence, self-determination', the Canadian RCT of Lecomte et al. (1999) had an exceptional wealth of detail including clinical outcomes using the Positive and Negative Syndrome Scale (PANSS) (Kay, Fiszbein, & Opler, 1987). These groups produced a temporary amelioration in delusions, perceptual disorganisation and paranoia. However, this experiment in artificial 'empowerment' was entirely designed and implemented by clinicians, within a hospital setting, and no sustained benefit could be detected in the patient group members 6 months after their 'graduation'. One of the earliest reports from British psychiatry also looked at a hospital-based discussion group. This used a narrative, life story approach for patients with schizophrenia:

What comes through most strongly are the sufferings of these lives, not as a passive register of a set of pains, but as the collective articulation of particular life histories within a particular social history, of sufferings that are individually felt but also exposed, interpreted and combated within a collaborative enterprise. (Barham, 1984).

Mutual aid groups exist for a variety of physical health conditions. Using a before-and after design with an economic evaluation, Lorig et al. (2001) followed up 489 patients with different chronic conditions who took part in small groups with a peer-instructor. These groups reduced the risk of depression associated with physical illness, at a cost of US \$200 per participant. Valuable advice came from Andrea Nelson, Editor of Cochrane Wounds Group, that we should search for outcomes such as 'mastery experiences', problem-solving and improved self-efficacy where UK groups had adopted Self-Management Programmes, a specific form of mutual aid where peers 'expert patients' lead a self-management programme based on US chronic care models. Backwith and Munn-Giddings (2003) confirmed recent use of such Self-Management Programmes (SMP) for mental health, within some British mutual aid initiatives. A widely cited British author (e.g. four references, below) is Judy Wilson, the director of the Long-term Medical Conditions Alliance. The current voluntary sector view in the UK (Rigge, 2003) is that 'self help groups should be a force to be reckoned with as well as an invaluable resource to the NHS'.

There is a long history of professional suspicion of lay contributions to mental health care. Professor Ernest White, who became President of the Medico-Psychological Association (precursor of the Royal College of Psychiatrists), wrote about 'the treatment of the medical attendant and management by the nurse being interfered with' by patients' contact with friends (White, 1903). The reported disadvantages of relying on mutual aid include 'the lack of

accountability, vulnerability to colonisation, inequalities in distribution, instability and fragility' (Gay, 1988). The following is a typical British anecdote, in this case from a women's eating disorders group: 'The doctor refused to put up our poster. He said people would pick up bad habits from each other' (Wilson, 1994b).

Wilson (1999) identified potential risks related to sponsorship for groups from the pharmaceutical industry. However, most published anecdotes relate to mutual misunderstanding between user-led groups and clinicians. For example, small voluntary groups may seek to influence service development within a mental health 'collaborative', but encounter the potentially devaluing response shown by a psychiatrist: 'there wasn't really a mechanism for somebody to have a representative function, rather than just an individual patient [sic.] function' (Robert et al., 2003).

None the less, professionals in the UK have sometimes identified mutual aid groups as a positive resource, for example providing 'information, help lines and support' for people with schizophrenia (Kuipers, 2001). Within alcohol and drug rehabilitation, Chacksfield (2002) observed 'self-help groups are an especially valuable support'. The greatest challenge in the literature is the heterogeneity of outcomes attributed to different UK groups. For example, the Health Development Agency (HAD) reviewed the evaluations of 54 art-based projects and listed 128 different 'outcomes' (HAD, 2002).

Methods

Previous reviews, such as the Netherlands meta-analysis, have been inconclusive because of 'the dearth of studies on self-help groups' (den Boer, Wiersma, & Van den Bosch, 2004). Initially we sought English-language literature, published or unpublished, from any country. We considered work originally written in other languages if a summary was available in English and the authors had personal contact with these researchers. First, author AB compiled contextual material related to British psychiatry and substance misuse. Author WC was formerly a trainer in the UK Critical Appraisal Skills Programme (CASP), and the material for inclusion was assessed by him in 2004, following repeated checks with author CM-G about matters of interpretation and salience. The material most relevant to this review would identify the mental health needs of group members, any outcomes of group attendance (positive or negative) and any relationship between mutual aid groups and clinical services. Because our initial scoping found outcome studies from the UK rarely were reported, we sought to retrieve studies from multiple channels (NIH, 2000) for our attempt at a synthesis.

Sources

Abstracts of published papers were sought from Medline, CINAHL, and the British Library ESTAR. For example, in the data set Medline 1966–2004, the search term 'psychiatry, substance misuse and self-help group' identified 348 papers, from which four abstracts relevant to our objectives were pursued, and the search 'psychiatry, substance misuse and mutual aid group' identified seven papers, of which one was relevant. We searched for the most cited papers in the Web of Science. Relevant thesis abstracts and reports were found through the web sites ASLIB, COPAC, the UK Electronic Library for Social Care, the Institute for Alcohol Studies, the SHAMARN network and Mental Help Net. In some uncertain cases where theses that might have been relevant were identified, a search for published papers by the same authors was conducted using Medline and CINAHL. Much of this 'grey literature' gave very little description of the group members involved, so additional details of groups were sought from Patient UK, the Mental Health Foundation and directories recommended for the National Health Service (Department of Health, 2001; Lundbeck, 2002). Many British databases had surprisingly little material on self-help/mutual aid groups, e.g. the National Electronic Library for Health, the ESRC Regard or NMAP. A key starting point for finding evidence was the postgraduate research work by Munn-Giddings (2003), with 307 references.

Compiling the review

The quality of many papers and reports was poor, especially in terms of offering methodological details. The most prominent groups were those awarded national or

international prizes for mental health, but the judges' criteria were never recorded. British controlled trials (e.g. Milligan, Bingley, & Gatrell, 2003) were rare and their statistical power was always limited by a small sample size. To summarise diverse studies, we attempted to undertake a new approach recommended by the Social Care Institute for Excellence (SCIE, 2003): *metasynthesis*. This review may appear a crude application, compared to the definitive model of metasynthesis expected from the National Institutes of Health Programme in 2005 (NIH, 2000). Our tentative findings on 'mutual' aid were tested with participants in several multi-disciplinary meetings, beginning with discussions at the Royal Society. Following these helpful discussions of our draft review, our attention was drawn to a small number of additional reports, such as a recent RCT (Chien, Norman, & Thompson, 2004) involving 48 family carers in Hong Kong, and emerging policy guidance (Appleby, 2004; Mental Health Foundation, 2004; Scottish Intercollegiate Guidelines Network (SIGN), 2004).

For this review we employed an operational 'definition' of mutual aid groups developed by Munn-Giddings and Borkman for a multi-centre collaboration due to report in 2005 (Mental Health Foundation, 2004). There is not an internationally agreed definition of mutual aid groups but there is consensus among researchers of at least three commonalities (see Box 1).

Box 1. What are 'mutual aid groups'?

- They are run for and by people who share the same health or social issue
- Their primary source of knowledge is based on sharing direct experience
- They occur as voluntary collectives predominantly in the third sector of society as opposed to the statutory or private sectors

Results

There are groups, and groups – or are there?

The classification and subsequent inclusion or exclusion of groups from the literature reviewed appeared to be vital, when this project began. The most readily accessible, published American literature is dominated by 12 Step programmes like Alcoholics Anonymous, or more highly structured programmes reminiscent of Lao Tzu's 'a journey of a thousand miles must begin with a single step'.

Estimates suggest there are between 23,400 and 49,000 local self-help groups in the UK (Munn-Giddings, 2003). Some local groups are aligned with national support that has very extensive use. For example, the Depression Alliance (2008) claims 'This web site receives over 500,000 page views every month'. In some areas, mutual aid groups may have a wider geographical coverage than specialist psychiatric care. For example, Lemouchoux, Millar, and Naji (2001) found only a single inpatient bed for eating disorders in Scotland; there were at least nine local self-help groups. The mental health and substance misuse groups found in the UK are a mixture of both inward oriented (for personal change) and outward oriented (for social change), using the terminology of Nylund (1998). Emerick's (1991) 'social movement' description is the most cited typology, e.g. in the study by Hatzidimitriadou (2002) of helping mechanisms in 14 English groups.

Not only is there a considerable overlap between psychiatric and/or substance misuse caseloads and the membership of self-help groups, this overlap may apply particularly to the most severe cases (chronic anxiety: Graham et al., 2001). For drug users in the community, this ecological overlap between psychiatric and voluntary help (Caan, 1994) enabled more patient-centred case management. Wilson (1995) produced guidelines for professionals working with mutual aid groups, and examples are emerging of formal collaboration between clinicians and volunteers (Gillam, 2002).

Overall, within the wider mental health and substance misuse care systems, mutual aid groups appear to demonstrate the pattern of 'collaboration and duality' described by Ben-Ari (2002). However, with members whose experience is so diverse (e.g. bereavement, parenting, offending, trauma, severe mental illness or addiction), it becomes necessary to read the literature with the caveat that each group 'writes its own history' (Thelen, 1992).

What types of outcome are reported?

A few papers from the UK have resembled the US literature on 12 Step programmes. For example, the cohort study of Narcotics Anonymous using standardised measures (Christo & Sutton, 1994) found a gradual but substantial improvement in self-esteem and a reduction in anxiety among group members.

In contrast to the US, many UK groups were activity-focused, and may have been set up initially with health service funding, or by professionals usually employed in health services who undertook additional roles. For example, the Dance Action Zone in Leeds (2008) initially included a small youth dance group. Spontaneously, young people began to replicate these mental health-promoting groups, reporting 'you feel important, you feel like all the rest of the group is depending on you'. The Kidderminster initiative for young men with severe mental illness (Music Workshop Project, 2003) was set up 'to encourage interpersonal communication' by a nurse, in his own time. The members themselves subsequently transformed this music-based group into a self-sustaining business. The experimental group of Chien et al. (2004) showed a similar transition from professional facilitation to peer leadership, with a nurse guiding the first two meetings and then a carer taking on this role for the next ten meetings. This group work was seen as responsive to families' values of 'solidarity' and 'interdependence', producing major improvements in family routines and modest but significant benefits to mental health.

A feature described for many groups was their constantly evolving nature. The winners of the 1996 Department of Health Voluntary Sector Mental Health Award (Lifecraft, 2000) continue to demonstrate remarkable flexibility in the groups they host in Cambridge. Given that their users are self-selecting, this may be a necessary requirement for sustainability. In their work for Barnardo's with young offenders who identified a variety of mental health needs, McKay and Caan (2002) had to address the severe social exclusion of these adolescents through developing a number of different activity groups (including community artwork, drama and music).

One of the first comparative evaluations in the UK compared a gardening group and other activities for older people (This week, 2002). Preliminary findings from this non-random controlled trial of a gardening group used the SF-36 questionnaire (RAND, 2008) as a standardised outcome (Milligan et al., 2003) but had insufficient statistical power (only 20 participants completed the follow-up) to confirm the apparent improvement in mental health scored by some members. Qualitative data were more abundant and revealed positive experiences of 'mental wellbeing' specific to the shared activities of the group. The subjective feel of the gardening group may be indicated by the voices of these three members:

- 'It was communal, everyone helped each other'
- 'you've been talking to people and discussing the gardening and this and that and other...it's gave you that pleasure to know that you've been and enjoyed it...you feel so different'
- 'there's different characters, we've all sort of gelled, and talk to each other a lot, and ask, you know, not to be frightened to ask anybody something, you know' (Milligan et al., 2003, pp. 38–39)

Work done independently of that study, on gardening and conservation groups for people with either mental illness or learning disabilities, found an unexpected social outcome that has been termed embracement (Burls & Caan, 2004). Following up members of a conservation group over a year, Burls (2007) recorded outcomes such as: 'respect', 'everybody working together for the same thing', 'helps spiritual growth, nurture and pride'.

Horticulture is more widely developed as a normal pastime in the UK than in the USA. An allotment group that was evaluated as a collaboration between a community mental health team and a gardening charity (Fieldhouse, 2003), revealed member-centred outcomes around engagement, peer learning and confidence, for example:

When you are with other people you can try things out – can't you, really. 'Reality testing' I believe it's called...I mean, you get some feedback to what you say, hopefully. You wouldn't get it if you walked down the street and spoke to somebody because they'd think you were a lunatic or something. (Fieldhouse, 2003, p. 291)

One of the most ambitious groups we discovered emerged during our attempts to test our preliminary findings at meetings. Morgan (2004) shared the results of her action research with the homeless mentally ill in Glasgow. This Barnardo's mutual aid group, using ocean sailing as its shared activity, reported intermediate outcomes of 'self development' and 'further skills' leading ultimately to employment.

Not all novel groups use collaborative activity to help their members. For example, an interesting new inward-oriented educational model, imported from Germany, is the 'psychosis seminar' begun by Thomas Bock in 1989 in Hamburg. At various times, these seminars may include patients, family carers or doctors. There are very few accounts in English, but this is the subjective experience of one early member:

But above all, the exchange of experience, means a liberation from psychiatry writing our psychoses off as a useless experience, which forces us to deny our own personal history. It also means a liberation from the inner isolation of having to keep silent. (Buck, 1999)

Similar determination to make experience liberating is also found in some outward-oriented advocacy groups, such as a group for drug users with hepatitis (Efthimiou-Mordaunt, 1998): 'All our loss and pain must not be in vain'.

Another imported model mentioned in the literature is derived from experiences of HIV and AIDS. This is a very fluid hybrid of inward-oriented (buddy support) and outward-oriented (campaigning) approaches. In the 'junkies' union' model, mutual groups are made up of drug users who are still actively involved in drug taking behaviours. Supporters of this approach claim these groups operate like a self-policing force in the drug sub culture, encouraging responsible attitudes, such as healthier behaviour around syringe and needle sharing (Baldacchino & Rassool, 2006). The origins of such groups include the American group ADAPT and its counterpart in the Netherlands, the Junkibondens. Professionals have described these groups as 'a forum of promoting drug use' (Nelles, 1990). Anecdotally, high mobility of members and mortality of leaders limited any formal evaluation of these groups in London, although it is possible their campaigning has influenced UK policies in areas like the wider availability of methadone maintenance and the creation of some user involvement posts within drug services.

On both sides of the Atlantic, governments are showing an increased interest in the possible contribution of faith groups to health care. We identified a number of mental health support groups with explicit religious affiliations, but no outcome data from the UK were found. However, some novel models have appeared with the aim of engaging hard-to-reach groups. For example, one Primary Care Trust has developed a community reading group to involve South Asian women exposed to domestic violence (Salman, 2004). Its educational model aims at improved communication and self esteem.

The potential for harm

Possible adverse outcomes relate to the same condition: chronic fatigue syndrome was described in two articles (Bentall et al., 2002; Carelsen, 2003). For 95 British patients with clinical treatment for chronic fatigue syndrome, Bentall et al. (2002) found that poor outcome was predicted by membership of a self-help group. They suggested there was a conceptual dissonance between doctors and volunteers about the management of this syndrome.

Boundaries

In some settings there is uncertainty about the boundary between mutual aid and professional therapeutic skills. Bock, Gillam and Fieldhouse are qualified as a psychiatrist, mental health nurse and occupational therapist, respectively. However, they seem to have acted as catalysts for groups that gradually developed a life of their own. Boundaries become even harder to delineate in the 'Sick Doctors' study of Stanton and Caan (2003). For example, the Doctors Support Network provides non-clinical mutual aid by clinicians to clinicians.

To build capacity in primary care services for alcohol and drugs, Banks and Waller (1983) proposed long ago that 'a working partnership of the concerned agencies is ideal so as to enhance the resources available within the community. There is a scope for further initiatives in the community between statutory agencies and the voluntary sectors on combined treatment and training' and, whilst not the focus of this paper, it should be acknowledged that a wide variety of agencies including Social Work, the Probation Service, Criminal Justice Services and the voluntary sector are also major service providers. AA (2003b) is widely supportive of these partnerships with doctors, and a number of local AA groups meet in NHS premises. Scotland has led the way in the UK (Scottish Executive, 2002) instructing local alcohol co-ordinating committees to involve service user groups in development. The Scottish Intercollegiate Guideline (2004) on alcohol treatment in primary care recommends, for example, that alcohol dependent patients 'should be encouraged to attend Alcoholics Anonymous'. However, at the level of the English National Alcohol Strategy, the Government appear to be more interested in partnerships with the alcohol industry than in collaborating with groups of service users (Prime Minister's Strategy Unit, 2004).

Are there models for effective partnerships between psychiatry and self-help?

There is a complete gap in the UK effectiveness evidence. However, American observations suggest that 'faith in the psychiatrist' was associated with goal advancement in four mental health groups (Hodges & Segal, 2002). Mutual aid seems to function as an 'adjunct' to professional treatment. Kelly and Moos (2003) found that patients who initiated 12-step behaviours during treatment were less likely to drop out of such groups. Most importantly, both self-help and formal substance abuse treatment are independently associated with reduced alcohol and drug use (Kissin, McLeod, & McKay, 2003). The 12-step Facilitation Therapy findings in Project MATCH indicate that alcohol dependent individuals randomised to this type of treatment and showing low psychiatric problems were more effective in staying abstinent longer (Project MATCH, 1998). This means the benefits to patients are additive.

Where UK outcomes evidence is available for partnerships, it is in the parallel field of residential Therapeutic Communities (TCs). Many of these incorporate elements of mutual aid in groups. Author WC has been involved in the evaluation of several residential services, including a unique service for young people with frequent self harm combined with depression and alcohol or drug use (the Crisis Recovery Unit), whose focus is on therapeutic risk taking. The origins of this TC have been detailed by Crowe and Bunclark (2000), and our evaluation for service commissioners demonstrated marked prosocial changes over 6 months' participation. For an adult population who combine personality disorders with alcohol (55.1%) or drug (43.9%) problems, Norton and Warren (2005), at the Henderson Hospital, found significant improvements in measures like impulsive actions, self-esteem, depression and post-hospital service costs over the period of one year. However, these Health Service TCs include a high level of professional supervision that continues throughout the residential period, and so they differ in one significant respect from the definition of What are Mutual Aid Groups? (see Box 1).

On both sides of the Atlantic in the nineteenth century, 'dry' or 'sober' houses shared by groups of alcoholics for mutual support began to arise, and this type of residential mutual aid continues still, for example domestic 'refuges' for women who have experienced male violence (and often generations of substance use). In the UK we could find only anecdotal evidence, although in our 6-month pilot project for one Social Services Department, male morbid jealousy discouraged follow-up: ex-partners located, pursued and murdered two of the women in our easily located sample.

Discussion

Much US and a little UK evidence suggest gradual improvements in the members' mental well-being when involved in mutual aid groups. However, much UK literature refers to small groups based on collaborative activities like dancing or gardening. Their collective strength may be in the diversity of activities on offer. The evidence describes only subjective improvements, although these seem to involve a similar pattern of benefits across a wide range of mental health needs. Mutual aid groups with educational models are also developing for a few patient groups. Publication and author bias may have led to many more reports of positive studies than negative ones. However, reports of only one condition seemed potentially associated with poorer outcomes, after attendance at a group: chronic fatigue syndrome. Some transient groups may be more difficult to evaluate than long-lived groups.

As this review suggests, there is certainly a need for further UK-based studies to inform practice development. In keeping with the ethos of this article, there is a particular need to support projects that have experiential knowledge at their core, for example, user/patient led research building on the initiatives of the Strategies for Living Team at the Mental Health Foundation (Faulkner & Layzell, 2000). Through UK Home Office grants, opportunities are arising for small community groups to be trained to undertake more rigorous self-evaluation (Association for Research in the Voluntary and Community Sector, 2001). There is also scope for more reciprocal research, combining the experiences of professional and lay groups, utilising both quantitative and qualitative methodologies.

Sometimes the process of empowerment, where the patient feels the 'master of his fate' seems lacking in professionally based treatment models. The NHS has introduced an emphasis on choice, but the concept of choice in health provision is not applied to mental health and substance misuse as much as other areas (Forrest, 2004). A generation after Barham's study, many patients with mental illness or addiction would still recognise the limitations of provision that lead to a disabling 'loss of confidence in the viability and value of their life projects and the reconstruction of themselves as useless' (Barham, 1984, p. 184).

For many needs, mutual aid based on reciprocal trust and respect (HEA, 1999) may be a valuable adjunct to clinical care, suggesting the need for research based contemporary practice guidance on how professionals can best support mutual aid without undermining its peer based ethos. Partnership Trusts that combine health and social care may provide a good environment for this dual care (which occurs informally for many patients, already). However, boundary issues need to be resolved appropriately, before the clinician can legally and ethically delegate to these groups any clinical responsibility for the care of a patient. Drawing on 'expert patients' within established groups may help professionals shape future mental health policies, collaboratively. The value of building reciprocal and trusting relationships has been part of lay knowledge for millenia:

*'Though one may be overpowered,
Two can defend themselves.
A cord of three strands is not quickly broken.'* (Ecclesiastes 4: 12)

Notes

1. American Self-Help Clearinghouse – a keyword searchable database of...national, international models and self-help support groups. <http://www.mentalhelp.net/selfhelp/>
2. SHARMAN – a new collaborative national research network (1999). Originally supported by APU funding and held its first National Conference Framing a Future for Self-Help, chaired by Munn-Giddings, in June 2000. Other founder members were colleagues from the College of Health, Sheffield Hallam University and Self-Help Nottingham.

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