

Can support groups heal?

JAN GREENE BA(communications)

Patients with diabetes, heart disease or other chronic conditions that require lifestyle changes, and those with conditions that require a lot of coping, such as cancer or HIV, are hard to treat within the confines of a 10-minute office visit. Common sense and limited data suggest peers can help.

The problems of chronic illness are complex and require long term involvement, well beyond the resources of most practices. An adjunct that may work for some patients is the self-help or support group. Referring patients to talk regularly with peers facing the same problems can be a useful therapy, reducing patients' sense of isolation and providing a place to share information and concerns related to their disease and treatment.

It may be hard to imagine that sending your patients off to sit in a circle and 'share' is going to make much difference in their blood sugar levels. In addition, at present hard evidence is scant that such periodic social support actually changes the course of chronic disease. However, advocates of self-help argue that support groups make a real difference in patients' emotional wellbeing, which can be crucial to the kinds of difficult, long term lifestyle changes required by diseases such as diabetes, obesity and heart disease.

'Patient satisfaction does go way up when patients have a variety of psychosocial supports added to the normal system of care', says Ms Laurel Simmons, the founder of an online support group for bone marrow transplant recipients like herself. 'Despite the absence of evidence from controlled trials, compassion, common sense, and self-awareness tell us that many patients and caregivers need emotional support to deal with illness.'

With or without the encouragement – or even the knowledge – of their physicians, Americans have been flocking to self-help groups in recent years for everything from drug addiction to the stress of caring for a parent with Alzheimer's disease. A 1997 survey by Harvard University researchers found that about 7% of American adults, or 11 million people, had participated in a mutual help group in the previous year.

While many patients seek out such groups on their own, programs that make regular meetings with peers part of the treatment are becoming more common. Diabetes is a prime example. Both American Healthways, based in Nashville (formerly the Diabetes Treatment Centers of America), and the well known Joslin Diabetes Center in Boston use professionally led support groups as an integral part of diabetic care.

When Ms Laura Wingard was diagnosed with type 2 diabetes soon after her 40th birthday, her doctor referred her to short term educational classes and invited her to a once-a-month support group run by the practice, where she could learn how others were managing their illnesses. The first session made an indelible impression. 'There were a couple of veterans there, people who were diagnosed maybe 10 or 15 years ago, hadn't taken care of themselves, and were now facing complications', Ms Wingard explains. 'There was one man who was severely overweight and had lost the feeling in his feet and his hands. That's kind of an eye-opener. It gets your attention.'

Along with learning from others' experiences, support groups offer an intangible that cannot be replicated by anything a doctor can say or prescribe: the sense that the patient is not isolated in his or her disease. 'They help people feel less alone, more confident', explains Mr John Zrebiec, a certified diabetes educator at the Joslin Diabetes Center. 'They allow for the ventilation of feelings, help focus on how to change lifestyle and provide an arena for problem solving.'

Group styles vary

Women tend to use support groups more than men, but men can be drawn into support as long as it is structured. The weight management clinic at George Washington University, a 20-year-old scientifically based program, found that its support group concept just didn't work for men, who didn't like the idea of an open-ended arrangement involving emotional sharing. 'It was a disaster, we could never get the men to go', recalls Arthur Frank, MD, medical director and founder of the program. 'So one day we said we won't call it a group anymore, we'll call it a class. It was still the same group of people with the same leader and the same material, but it was approached in a more structured way and they were very comfortable with it. After three or four weeks they functioned as a group anyway.'

Professional versus peer leaders

It is also important to differentiate between professionally led support groups, often sponsored by a treatment centre, and self-help groups that are run by patients and their peers without oversight, such as Alcoholics Anonymous. Both types have their proponents.

Keith Humphreys, PhD, an Assistant Professor of Psychiatry at Stanford University, has studied self-help in addiction

Jan Greene was a freelance writer specialising in health care who was based in San Francisco at the time of this article's first publication in *Hippocrates* (from the publishers of *The New England Journal of Medicine*).

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treatment. He believes self-help without a professional is the best option for many patients. 'Patients tend to hang back more in the presence of a professional', he says.

Psychologist Dr Dianne Lindewall, who designed the support group component of the George Washington University weight management clinic, believes professional involvement can be crucial for illnesses such as diabetes and obesity that require a complex set of behavioural and psychological changes over a lifetime. 'The difficulty with self-led groups is that...they don't understand there are several ways someone can approach the problem, and this might not be the right way for you', she says. If the patient fails in a self-help group, he or she is more likely to blame him- or herself and have a serious setback.

Research is ongoing

The effectiveness of both types of support groups has been studied extensively, but researchers looking to set up classic double-blind studies have been stymied by the difficulty of quantifying human behaviour. You can assign one group to get emotional support, but how do you keep the control group from seeking it out? That is particularly difficult now that support groups have become so popular.

There was a lot of excitement in the early 1990s about the potential for support groups to actually improve cancer survivorship – a Stanford study conducted by David Spiegel, MD, released in 1989 seemed to show that women undergoing breast cancer treatment who participated in professionally led discussion groups survived about 18 months longer than those who did not. Subsequent studies have failed to replicate those results, and some hypotheses have been advanced about an apparent anomaly in the control group. Still, the study created a flurry of support activities for cancer patients.

Yet most of the findings on peer support are not as dramatic, and most recent studies have focused on improvements to patients' psychological wellbeing. For instance, the University of California San Francisco psychologist Dr Morton Lieberman, PhD, reported that widows and widowers who shared their grief with peers in regular meetings were less depressed and functioned better as parents than those who had to handle the loss on their own. Whether such improvements translate to better management of disease is less clear.

In a study focusing on the effectiveness of self-help meetings for drug and alcohol abusers, researchers led by Stanford's Dr Humphreys followed 2337 veterans through the year after their discharge from inpatient treatment for substance abuse. He found that a year later, 84.4% of the men either were still involved with a self-help group, such as Alcoholics or Narcotics Anonymous, or were still using the programs' principles. The researchers found those who participated in the self-help groups were less likely to use drugs and alcohol after treatment, developed richer friendship networks, and reported coping more effectively with stress.

Other studies have shown that self-help support for former mental health patients reduced their chances of being hospitalised, and that men with diabetes who attended education and a peer support group had better quality of life and less depression. Also, the diabetic people in the support group had better glycaemic control than those who received no intervention.

Web-based support

Meanwhile, the internet has taken off as a new venue for patients to help one another through the emotional turmoil of disease. The Joslin Diabetes Center, affiliated with Harvard Medical School, launched an increasingly successful online

support chat room in the last year. It has become so popular that two-thirds of its users are not even patients at Joslin.

Mr Zrebiec, the clinical social worker who moderates the online discussion, can offer anecdotal evidence that the chat room is prompting lifestyle change for some of the diabetic patients who participate. Over the previous several weeks, a woman had confided to her electronic compatriots that she could not manage her diabetes because an abusive relationship with her husband was overwhelming her life. 'This morning she announced to the group that she's leaving him', Mr Zrebiec relates. 'And she said the online support group had really encouraged her to do it. That's quite a dramatic lifestyle change.'

Despite such anecdotes, Mr Zrebiec would like to see researchers document the improvements in health that online support can provide. Some work is being done along those lines with other diseases. A small study sponsored by the Wellness Community and investigators at Stanford and the University of California San Francisco is following eight women with breast cancer in a facilitated online weekly support group to find out whether it reduces depression, increases survival, improves coping or lengthens time to recurrence. Other researchers at Stanford have initiated a larger, two-year study comparing patients with back pain who get online support with others who just receive a magazine of their choice.

Outcomes are also being tracked for the Comprehensive Health Enhancement Support System (CHESS), an online patient education and support website developed at the University of Wisconsin, Madison. Ms Fiona McTavish, project director for the breast cancer portion of CHESS, says the companionship is improving patients' quality of life, even if the data cannot yet show improved medical outcomes. 'I don't know if support groups change the course of the disease, but I can tell you it's a much higher quality of life', says Ms McTavish.

'They're living life now, they're not just waiting to die.'

Online support has some distinct advantages, Ms McTavish says: it is available any time of night or day, and it can be anonymous. In fact, most of the use of CHESS occurs between 9 p.m. and early morning, times when the emotional impact of a serious illness can keep someone awake with worry.

As for anonymity, it has allowed the discussion to go in directions that might not occur face-to-face. For instance, a recent topic that created lively discussion was about nipple reconstruction for women who had had mastectomies. 'They discussed all the details, including whether to get it tattooed or not so it's the right colour', McTavish says. Moreover, while the participants can remain anonymous with code names and passwords if they like, quite often the members who find out they live in the same area will set up face-to-face meetings and shed their cloak of secrecy.

The CHESS program is used by a variety of hospitals around the country for breast cancer, HIV, heart disease, and Alzheimer's caregivers, and is being developed for smoking cessation, prostate cancer, and asthma.

Self-help is a cost-effective alternative in an increasingly cost-conscious medical world, argues Dr Humphreys. 'We can't afford to assign everybody a social worker or an MD. We need something that's very inexpensive for each contact, and that's one of the good things about self-help groups. They are essentially free.'

Mr Zrebiec encourages primary care doctors to include referral to a support or self-help group as part of a treatment plan. 'Many patients will not seek out a group without their family doctor recommending it', he says. 'Most people need a gentle push from their doctor.'

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Reviewer's comment

Whilst there appears to be no solid clinical trial evidence of the benefits of support groups, there is certainly good anecdotal evidence in terms of mutual support and sustained friendship. Perhaps we need some sound sociological studies rather than purely biological and epidemiological studies, because quality of life for many patients is more important than mere survival.

The very existence of dozens of self-help and support groups in Australia points strongly to a benefit – not only in terms of information sharing but also in terms of mutual edification.

Dr John W. Dearin FRACGP, DipGer, DipRehabMed, MBioEth
General Practitioner,
Lithgow, NSW

Selected references

1. Galanter M. Zealous self-help groups as adjuncts to psychiatric treatment: a study of Recovery, Inc. *Am J Psychiatry* 1988; 145: 1248-1253.
2. Humphreys K, et al. Do enhanced friendship networks and active coping mediate the effect of self-help groups on substance abuse? *Ann Behav Med* 1999; 21: 54-64.
3. Lieberman MA, Videka-Sherman L. The impact of self-help groups on the mental health of widows and widowers. *Am J Orthopsychiatry* 1986; 56: 435-449.
4. Simmons D. Diabetes self-help facilitated by local diabetes research: the Coventry Asian diabetes support group. *Diabet Med* 1992; 9: 866-869.
5. Spiegel D, Bloom JR, Kraemer HC, Gotthel E. Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet* 1989; 2: 888-891.
6. Sibthorpe B, Fleming D, Gould J. Self-help groups: A key to HIV risk reduction for high-risk injection drug users? *J Acquir Immune Defic Syndr* 1994; 7: 592-598.