Objective: To describe and report on the influence of a consumer-organized and -managed self-help group on people with schizophrenia in Alberta, Canada.

Method: A brief questionnaire was developed and administered to all members attending a self-help group meeting. Group members provided additional information about the structure and organization of the group.

Results: All 33 members responded: 27 (82 per cent) reported that attending the self-help group had improved their mental health (mean number of attendances was 19.22), in contrast to four (12 per cent) who did not (mean number of attendances was 8.25); only five (15 per cent) who had attended the self-help group were admitted to hospital in the past year.

Conclusion: Consumer-initiated and -controlled self-help groups could be an effective community support to people with schizophrenia. While this pilot study lacked a control group measuring hospital admissions, further study would be worthwhile given the cost-effectiveness of this intervention.

Key Words: schizophrenia, self-help group, Unsung Heroes, community care

There is a remarkable paucity of information on self-help groups specifically for people with schizophrenia (1); however, there exists a broad literature on psychosocial treatments including group therapies (2) and a significant prevalence of community advocacy groups, as well as groups run by health professionals (mostly hospital-based). Self-help groups are differentiated from other groups by key factors that reinforce commitment to personal empowerment, experiential knowledge and interpersonal support (3,4). Despite the fact that it is widely acknowledged that consumer initiatives should be part of any modern health-care reform strategy, there have been few systematic assessments of the impact of self-help groups and certainly no evaluations of self-help groups for people with schizophrenia.

Thus, we report on the Edmonton chapter of a self-help group known as “Unsung Heroes” that is currently one of six in Alberta, Canada. Unsung Heroes began in 1991 as an information and discussion forum organized by a consumer associated with the Schizophrenia Society of Alberta. The name was selected because individuals facing the daily struggles with schizophrenia are real heroes but unrecognized by society. The Edmonton chapter has grown from an initial attendance of one to a membership of approximately 60. The Schizophrenia Society of Alberta and the Alberta Mental Health Board provide $4,500 annually to cover the costs of dinners, coffee, rent and movies. All the members and local coordinators of Unsung Heroes are people diagnosed with schizophrenia. There are no paid positions, and the budget is controlled by a treasurer who is also a consumer. The focus of the group is to educate members about schizophrenia and to provide a venue where people with schizophrenia can discuss their lives in a supportive, open and social forum.

The Edmonton chapter meets weekly for two hours. In the first hour, a presenter, often a mental health professional, speaks in an informal, interactive atmosphere with the group on a prearranged topic advertised in advance in the local Schizophrenia Society newsletter. These topics are diverse, ranging from new research in schizophrenia and medications to dental hygiene to diet. In the second hour, the members divide into smaller groups and discuss what has been “going on in their lives” since the last meeting. There are no constraints on what the members can discuss. The group ends with an inspirational poem. When a presenter is not available, the group will meet for discussion and socialization. In addition, the group also meets on one other evening each week to attend a social event, usually a movie. Once monthly, the group meets in a restaurant. The members assume the various roles and duties necessary to ensure the continuity of the group; the chair rotates weekly, but the coordinator is constant. The coordinator keeps a record of attendance of members.

Although Unsung Heroes is not considered by the members to be “group therapy,” one of the goals is to provide mutual psychological support through both good and difficult times. There is group reinforcement of positive behaviours and thinking, with the aim of improving the self-esteem and quality of life of all its members; thus, participation is very much encouraged.
Results

All 33 questionnaires distributed were returned. The results of the questionnaires are summarized in Table 2.

Six respondents (15 per cent) had been hospitalized in the past year, and all were hospitalized just once. Five of the six respondents had attended more than one meeting of Unsung Heroes. Four respondents indicated that they were admitted fewer times in the previous year and that they spent less total time in hospital. For the other two respondents, this was more than in the previous year; these two respondents were in hospital for 12 months and one month, respectively. The respondent who had been in hospital for 12 months had not attended Unsung Heroes in the previous year and was on a hospital pass for the meeting; only this person responded that Unsung Heroes had not improved their psychiatric health. The respondent who had been hospitalized for one month had attended all the meetings in the past year.

Twenty-seven respondents (82 per cent) felt that attending Unsung Heroes improved their psychiatric health. The average number of attendances for those who stated that Unsung Heroes improved their psychiatric health was 19.22 in the past year, compared with 8.25 for those who stated that Unsung Heroes did not improve their psychiatric health.

Discussion

Without professional involvement, most self-help groups collapse soon after starting (1). Unsung Heroes has been remarkable, given the longevity of the group, the reliance upon members for the organization and continuity of the group (the role of the coordinator appears to have been a key factor) and the sustained attendance of the members. Historically, mental health professionals have had little confidence in the ability of persons with schizophrenia to organize and administer groups (1).

Unsung Heroes encourages social interaction in a supportive and nonjudgmental fashion. Self-help groups may be categorized in four ways: groups who promote the illness model, groups who provide self-help in conjunction with treatment for illness, groups who see themselves as consumers and groups who see themselves as liberationists (5). Unsung Heroes would appear to be closest in philosophy to groups that provide self-help in conjunction with treatment for illness, and although the group does not attempt to provide therapy directly, it acts adjunctively through encouragement of empowerment and self-sufficiency. By helping members overcome their social impairments and disability, the group may support other aspects of treatment by improving the quality of life of people with schizophrenia and potentially contributing to a reduction in relapse rates and hospitalization. Thus, Unsung Heroes shows similarities with other self-help groups in this regard (6).

Many persons with schizophrenia, even those who benefit from medication, continue to have disabling residual symptoms and impaired social functioning and may relapse despite medication adherence (2). While pharmacotherapy can improve some of the symptoms of schizophrenia, it has a limited effect on the social impairments that characterize the disorder and limit functioning and quality of life (7). The effects of Unsung Heroes would appear to be greatest in these domains, although it is difficult to define the actual processes. The group views itself not as treatment-orientated but as a safe forum for patients to socialize after the treatment day is completed. It is possible that the quality of life of its members is increased simply because they are able to get out and socialize with their peers on a regular basis.

Although the hospitalization rates for the respondents are encouraging, these are clearly related to many other aspects of their treatment and local community services. Nonetheless, this finding is consistent with the literature in this area, particularly regarding self-help programs for discharged psychiatric patients (8–10). It is also possible that patients who are hospitalized less often are also preferentially attracted to such a group and willing to complete questionnaires, while those that are more ill are less likely to attend or participate in program evaluation.

Respondents who indicated that attending Unsung Heroes improved their psychiatric health had attended more frequently than those who did not. This difference may be owing to several factors. First, perhaps the more a person
attends, the greater are the effects of the group. Second, perhaps the patient who is too ill to attend regularly is unlikely to benefit from the program. If symptoms are not under control, the patient will likely attend less and receive fewer benefits even when attending. This is consistent with the concept of different needs during different phases of schizophrenia, but whether the group actually improved the psychiatric health of the respondents is impossible to determine from this information. However, it is encouraging to find that this many people with schizophrenia perceived that attending a social group was beneficial to them and contributed to a decreased need for hospitalization. Although the results from this survey are interesting, clearly more research is needed to determine whether there are other self-help groups for people with schizophrenia and whether attendance and participation in such groups leads to an improvement in outcome when studied systematically.

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