

The study circle as a tool in multiple sclerosis patient education in Sweden

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Objective: Patient education plays an important role in the management of chronic diseases that can cause disability and predictable psychosocial problems. Quality of life assessment in multiple sclerosis (MS) has confirmed that psychosocial complications related to working life, marriage/partnership, and the family often occur. Furthermore, symptoms such as fatigue, pain, and sexual dysfunction have a great impact. We wanted to develop and implement study circles to promote the patients' abilities to meet such common problems and to provide a network where they can be autonomous and develop appropriate strategies in self-care and existential problems.

Methods: Together with the MS patient organization and a study association, we have arranged study circles for patients with MS, thus providing structured information according to a pedagogic model. The patients are encouraged to work together in groups to learn about the disease and its key symptoms, to develop strategies to master these symptoms in everyday life, and to make necessary changes, ie, self-care management. The programme also contains handicap policies.

Results: Fifteen study circles with a total of 105 patients started during the first year. Fifteen circle leaders were approved. A focus interview showed that the patients are highly satisfied but also revealed some problems in interactions with health care professionals. The study circles were included in a wider project from a newly started multidisciplinary centre for health education for a variety of chronic diseases causing disability, which aims at becoming a regional interface between the health care system, patient organizations, and educational services.

Conclusion: The study circles have an important role to play in the management of MS. Good organization is required to make such a project work since health care services do not normally work so closely with patient organizations and educational services.

Practice implications: Study circles that are permanently established and function well are of great help for the patients and the work at the MS clinic is substantially facilitated. Health care professionals also gain from the arrangement by learning more about the self-perceived impact of the disease.

Keywords: multiple sclerosis, patient education, pedagogy, health care, self-care, qualitative research

Introduction

Information requirements in MS

Multiple sclerosis (MS) management is a broad and complex issue, dealing not only with the medical side of the disease, but also with the psychosocial and existential consequences for the patient. These psychosocial problems *per se* also have medical effects which must be diagnosed and treated. Patient education is an important foundation for handling these psychosocial problems and when motivating the MS patient to improve coping, compliance, self care management, and quality of life (Baker 1998; Box et al 2003). This includes following prescribed medication and physiotherapeutic training, learning about the disease, and coping (Rieckman 2004).

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Consequently, these matters concern pedagogic and didactic issues: what information needs to be given, at what stage of the disease, by whom, and in what form. The scope is extensive. In our previous work (Landtblom et al 1992) we have identified at least four different didactic stages: the patient with MS must understand and accept the diagnosis; learn about the disease; inform others about the disease; and finally deal with existential questions such as thinking about life changing strategies and carrying them out. Some of these issues are not purely didactic but include emotional and psychological factors. It is therefore important that people from the medical profession are involved (Hatzakis et al 2003; Heesen et al 2004).

A structured information approach

Several scientific reports (Box et al 2003; Rieckman 2004; Heesen et al 2004) and our own experience show that it is useful to apply a structured approach, identify the initial crisis reaction, and separate it from the other issues mentioned above, because the crisis reaction often inhibits the ability to understand and remember information. This crisis is not always evident to the doctor/nurse. It may appear that the patient accepts the diagnosis without problem or just a mild psychological reaction. Nevertheless, many patients have a delayed or hidden crisis that can easily be missed and which motivates a rapid follow-up after the diagnosis has been given to the patient, as well as direct questioning on this topic. Immediately after receiving the diagnosis, the patient is often given comprehensive information on MS and the treatment that is planned. However, the patient has usually great problems in understanding and remembering such information correctly because of interference from the crisis reaction. Learning about their disease, how to manage key symptoms, ie, self-care, and how to inform others about the daily consequences of MS, should be focused upon after the initial crisis. These matters are also of great concern later on, as the disease develops into new phases, particularly the secondary progressive phase. Some investigators have focused on the problem of delivering appropriate information in different situations and stages of the disease (Hutchings 1993; Baker 1998; Box et al 2003; Heesen et al 2004; MacLean and Russel 2005). Important experiences from other areas can be mentioned in this context, for example in the shape of structured self-management programmes employed in other chronic diseases. One interesting example regards arthritis where classes are taught by lay teachers educated at an arthritis centre (Lorig and Fries 1986). It is also worth mentioning supportive techniques such as social

problem solving and cognitive-behavioral therapy that have gained much recognition and are used in situations such as life transition, substance abuse, family conflicts, suicide risk, stress, and a variety of health-related problems such as cancer (Nezu et al 1998; Chang et al 2004).

Information capacity and information venues

There is a distinct need to increase information capacity, since an ordinary clinical visit does not have the flexibility or time for the individual needs of the patient. A conventional clinical visit is characterized by an information flow from the specialist (doctor/nurse) to the patient, which confirms the lower medical status of the patient. Furthermore, a visit to the doctor traditionally does not allow peer guidance which could be of great help in increasing patient autonomy. New, interesting strategies have been tested, for example telemedicine/telephone contact with patients in order to introduce different topics such as peer support programmes (Mohr 2005) and energy-conservation education (Mills and Allen 2000; Finlayson 2005). Some have focused on the relatives' situation (Mutch 2005) while others have aimed at increasing self-care (Embrey 2005).

The continuous need for relevant, current, and specific information can be met in several ways. There is the initial individual medical information regarding diagnosis and treatment given by the MS-doctor, followed by appropriate information and training by the MS-nurse/paramedic, or MS-team. In Sweden, for instance, there are often hospital-based short courses for patients led by medical professionals, some of them specifically aimed at the newly diagnosed patient. They are called MS schools. In many hospitals there are MS physical training groups led by paramedics where structured information about the disease is provided. Support is also given by local patient organizations. Innovative strategies can be included like the structured telephone guidance mentioned above (Finlayson 2005) and also other forms of strategic support such as the motherhood decision aid (Prunty et al 2008). We think that there is a significant lack of supportive educational opportunities for MS patients in general.

Swedish study circles

Sweden has a long experience of study circles reaching back to the temperance movement (teetotalers) in the nineteenth century. Study circles have always been the core method used by The Workers' Educational Association (WEA) which was started in 1912 by the Social Democratic Party, some

workers' unions, and the cooperative movement. They were also used in health-promoting activities at both community and individual levels (Strombeck 1991). The WEA has a large number of member organizations including, for example, approximately 45 patient associations that are members or have a membership agreement. Most patient organizations have traditionally gained support from WEA for several decades. The patient organizations can thus use WEA for support when initiating activities like for example education or political manifestations. The pedagogic principle used by the WEA is characterized by a democratic view of life where weak groups in society are highlighted, such as people with chronic diseases, the unemployed, single women with poor education, immigrants, etc. The basic principle of these study circles is described by the motto "The participant is an expert".

Weekend courses and MS schools

In 2001, one of the authors developed a weekend course for patients with MS and later led these on a regular basis. The courses provide basic information about key symptoms (Nortvedt et al 1999, 2001a; Landtblom et al 2004), medication, psychosocial problems, physiotherapy, and recent research. Key problems were discussed in small groups, and the results of these discussions were presented in the main forum. Questions included informing others about one's diagnosis, how to structure daily life in the family, how to develop energy-conserving strategies, how to perform changes at work in order to obtain an optimal situation such as shortening working hours or avoiding tasks that have become too heavy or too complicated because of the disease. In 2005, this course was expanded into study circle material, "Living with MS", which is accessible for all MS patients in Sweden (Landtblom and Ekbladh 2005) through collaboration with WEA and a patient organization (Organization for Neurologically Handicapped People [NHR]). Expenses were covered by a pharmaceutical company.

In our county there are two hospitals (Motala, Linköping) that have developed MS schools with about 5–8 meetings in groups of 5–8 patients, including activities like lectures or open discussions with participation of the MS doctor, the MS nurse, the physiotherapist, the occupational therapist, and a social worker, respectively.

Aims

Our aim was to introduce the study circle, "Living with MS", as a tool for disease-specific education and empowerment of persons with MS and to link it to corresponding activities for patients in the hospital. Thus we wanted to increase

patient-related information capacity by increasing regular hospital-based MS patient schools locally and offering well-functioning groups of patients from these courses for incorporation in study circles run by a study association. We also wanted to evaluate the effect of the study circles scientifically.

Methods

Participants and leaders

In Östergötland county (420,000 habitants) there are 684 patients with MS registered in the National Swedish MS register. They are mainly followed up at the University hospital in Linköping, and the General hospitals in Norrköping and Motala. "Client leaders", leaders from the study association WEA, and health care professional leaders were engaged in the study circles. "Client leaders" were experienced MS patients with a balanced view on life and with experience of the difficulties caused by the disease, which enabled them to understand and support others with MS. Our aim was to have a leader pair for each study circle combining a health care professional or a study association teacher with a client with MS.

Recruitment

After participation in the hospital-based MS schools in Motala and Linköping, several study circles were formed. In Norrköping, where a MS school was lacking, the patients were instead recruited by the local patient organization (NHR). Fifteen circles totaling 105 participants in five cities were established during the first year. The participants were 75% female. Mean age was 40.5 years. The schedule for a study circle was sketched for groups with 5–8 participants meeting 5–8 times outside the hospital.

Consent

The participation in the study circles was voluntary. Informed consent was given by the participants who completed a questionnaire and by the MS patients who took part in a focus interview, see below.

Training

There were two types of specialized courses for study circle leaders, firstly a pedagogic one with a duration of three days to explain and teach the pedagogic principle of WEA, which uses problem-based learning to outline the specific experiences of the patients/clients. A neurologist also directed a one-day teaching course on MS. Patients, doctors, nurses, and leaders from the study association took part in both courses. Fifteen leaders were approved.

Compliance

There was a motivation to join the meetings and a high general compliance (around 80%) in all the groups counted together. Symptoms of MS now and then made it impossible for some participants to join the groups at all planned occasions. At a group level, this turned out to be a problem, since some groups were small from the beginning (5 participants) and the size thus easily reached a critical limit.

The intervention

The pedagogic principle of the study circles

A two-step information strategy was used. Most study circle participants had previously joined a hospital-based MS school. The basic pedagogic principle of the study circles is described by the motto “The client is an expert”, and the overall aim is to identify key problems and learn how to master them.

The role of the study circle leader is to guide and to prevent individuals from dominating the discussion according to their own needs. The study circle leader is normally not an expert in the field but has some pedagogic education following the principles mentioned above. The pedagogic method includes: the identification of a specific problem which the participants choose to discuss; “brain storming” to get an inventory of the various aspects of the problem; a structured analysis of this problem and ways to solve it. After this a structured plan of action is developed in order to achieve the changes necessary. The participants are encouraged to use the power of the group to achieve such changes. This may be political lobbying to improve general or local health care, spreading information, etc.

Measures

For the assessment of the project we have decided to use a qualitative technique along with a quantitative measure in order to describe the effects of the study circles in a scientific way. We have thus started to perform focus interviews (Graneheim and Lundman 2004) among the MS patients. We have also performed conventional interviews with the two types of leaders. Later, we identified the Leeds MS quality of life scale (Ford et al 2001) as an appropriate instrument for evaluation, distributed before and after one semester at a time in the study circle. This is a patient-completed disease-specific measure of quality of life validated in a community-based population of people with MS. The eight-item scale demonstrates a closer association to well being than physical function and has good internal consistency and test-retest

reliability. There are virtually no floor or ceiling effects for the scale. The instrument is brief, easy to use, and practical to administer. This suits our goals for evaluating the effects of the study circles in the future.

Analysis

Six female participants of a study circle were interviewed in a focus group after having finished their fourth semester. This was made by one of the authors who was not a study circle leader at the time. Open-ended questions regarding the positive and negative experiences from the study circle were posed. The interview was tape-recorded and afterwards transcribed verbatim. The text was analyzed in line with content analysis (Graneheim and Lundman 2004). Meaning units were identified according to a well known procedure (Graneheim and Lundman 2004). The basis for this division did not follow common grammatical and linguistic rules, but was rather made where a shift of meaning could be discerned. In the next step of the analysis, similar meanings of the meaning units were grouped together into subthemes, which finally were brought into themes. Each of the themes reflected the experiences perceived by the participants in the study-circle.

The distribution of the Leeds scale was incomplete, and there was a major decline of returned questionnaires.

Results

General procedure

The circles worked initially more or less according to the content of the study circle material/book “Living with MS” that provided basic information regarding pathology, symptomology, medication, training and management strategies with the aim to facilitate for the participants to develop a new life strategy by solving private problems and achieving genuine self-care. Key symptoms/problems in MS such as fatigue, cognition problems, sexual difficulties, and sex life were focused upon. The circle members were encouraged to identify such key problems, to analyze them in a systematic way, to collect necessary information, and begin the process of change. This is a way of problem-based learning (PBL). Focus was always transferred from the individual to the group level, community level, regional level, and the national level, a political strategy that gains those with MS and others as well. The circles enabled reflection together with others on life in general in order to develop adequate life strategies, and to improve the individual’s situation by coping. Participants often wished to continue attending a study circle after the majority of

MS information was debated, ie, after about one year. They were then given the opportunity to stay in the group which acted as a reference group and the participants could choose another main theme of their own choice, MS-related or not.

Some examples of actions that study circles performed during the first year were: going to local businesses with a demand of increased parking places for handicapped, going to the local press with a demand to spread information about a newly built pathway for handicapped in a famous nature resort, going to local politicians with general information about the disease and a specific demand to get regular rehabilitation for MS patients.

Almost the all study circles left the double leadership after one-two semesters. They went into a phase where the circle leaders recruited from the study association and the health professionals eventually moved into the background, which left the main responsibility with the client leader, but the health professionals kept contact with the group in order to help and support when needed and also help plan future activities. Future plans are to involve double leaders for new groups and keep both during the first year.

The investigation by the Leeds scale showed a major decline and could not be evaluated.

Interview with three health care professional leaders

Health care personnel reported that important issues could be discussed in detail in the study circles, which they felt did much to reduce the workload at the MS clinic. Patient integrity, however, was a problem because the nurses felt that they could not report potential participants from their patients due to confidentiality issues. On the other hand, the patients themselves who were often forgetful or ambivalent did not always contact the study organization as planned.

Interview with three leaders from the study association

After having read the study material "Living with MS", the groups easily found ways to proceed with their discussions by focusing on common problems and how to solve them. The leaders felt that they could decrease their participation and eventually see the groups occasionally. Several groups had started activities aiming at a work of change in their community such as defending the proper use of parking places for handicapped, spreading information about the activities of the patient organization, or demanding cooling garment as a free subsidized therapy from the hospital.

The common opinion was that the double leadership was most important in the beginning.

Focus group interview with MS patients

The discussion in the focus group thus revealed some key issues of meaning presented in the following themes:

- Common feeling of solidarity with the subthemes: From loneliness to solidarity; Empower each other; Sharing difficulties; Show vulnerability; Solidarity can get strenuous and hard; The relatives don't understand.
- Piece of good advice with the subthemes: Show the children; Sharing advice; Training urology problems; To be open with the injections in the family setting.
- The need for professional support with the subthemes: Professional support should be accessible to the study circle when a participant needs it; To be close to the doctor and the MS nurse; Difficult to support a fellow patient.
- To go on with the subthemes: To be inspired by others; To try to do the same difficult things that someone else has done.

All participants regarded the study circle as an indispensable resource in daily life, because "together we are stronger" and "we empower each other". The participants would not give up their planned meetings every two weeks. In the beginning the focus was to learn about the disease but later on this need decreased and was replaced by common discussions mainly on obstacles in daily life and specifically due to the disease. The common feeling of solidarity and giving each other good advice were different themes. There was a high acceptance for complaining and letting out one's feelings of harm and irritation. The participants often encountered misunderstanding and negative attitudes from their community environment which caused anger and sorrow. When they were together, they laughed about it. The advantage of being participants of a patient group was highlighted, because it made it possible to be honest with one's feelings and release them. It was a big relief to hear others report their similar experiences because it made one feel less lonely and also gave creative input about helpful strategies. This sharing gave hope to participants who then wanted to try harder. Another important theme was "To go on". Interestingly, the participants wanted to keep their relatives out of these circles in order to be totally honest with their situation and not needing censor their discussions. On the other hand, they wanted their relatives to get support in another setting. The presence of family members or healthy persons made the participants try to hide many

symptoms and thoughts in order to spare them. The problem of supporting another person with MS raised questions about how far one should go: where is the border of their responsibility? The potential for support from the health care professionals was underlined, which was something that was not regularly arranged. One disadvantage with the study circle that was mentioned by all was the fact that the border between peer support and a need for help from the health care professionals was hard to distinguish when a participant is struck by severe problems. The need for contact with a professional MS team in such situations was pointed out. Also it turned out that some other participants had left the group one year earlier because they did not want to “talk about the disease” any longer, but rather wanted the group to turn into a common study circle with another theme, such as “novel reading” or “cooking”. This need was not yet met by the study association. This study circle thus had undergone a kind of maturing process, where some participants were not fully satisfied and also had not got a new alternative. The strength felt by the participants that stayed together made them want to expand the group to new people with MS, in order to share their positive experiences.

The focus interview revealed a genuine healing power within a mature group such as this one, but also problems that have to be resolved in order to make the activity safe and good for all.

Discussion

The MS study circle uses material reminiscent of self-management programmes (Lorig and Fries 1986), but goes one step further since existential questions are regularly focused upon. The possibility of prolonged participation – over several years – is also a specific feature of the study circle when it develops into a reference group. Another important difference between a study circle and a self-management programme is that the participants decide which issues should be taken up and when. The study circle can include strategies similar to the problem-solving concepts used to support cancer patients (Nezu et al 1998). However professional leaders or therapists are seldom involved. The study circle strategy relies on the common experience of the participants and the questions they choose to raise. This peer strategy enables expansion of activity that is greater than that should the help of professionals be required.

There is some scientific evidence that quality of life can serve as a predictor of deterioration, ie, change in disability (Nortvedt et al 2001b). This indicates that the ability to cope may have an impact on the progress of the disease itself.

Such data strengthens the importance of activities such as study circles.

Pedagogic research shows that learning is enhanced when the student is active, which is the theory behind PBL, a method practiced at the medical faculty in Linköping (Toohey 1999; Dahle et al 2002). Interestingly, PBL in many respects reminds of the pedagogic principles applied in our study circles. This is an advantage since medical students have shown interest in participating in our study circles, which led to an interesting collaboration between the hospital and the university. Such a process might also be facilitated by The Forum of Health Pedagogics, a recently founded multidisciplinary centre in our county, which facilitates the health education of patients and their relatives by creating an interface between the patient, patient organizations, and health care and educational services.

Our intention is to make this permanent according to a Norwegian model (Hopen and Vifladt 2004). Another link in activities involving the MS patient’s need for information and discussion is the Swedish MS register in which most MS patients choose to participate (Landtblom et al 2007). Here fundamental clinical data from the medical file is recorded in a database which is accessible to the treating physician/nurse. Also included is a check list where the patient and the doctor can list current symptoms, which in MS can be many. There are also questions concerning quality of life. Physicians and nurses can use the register when hospital-based courses and study circles are planned and conducted, partly to assist the design of the course/study circle but also for future evaluation purposes. We have found this practical. Recent knowledge about the perceived social situation of people with MS reveal that the patients often experience a complicated mixture of being ignored and subjected to persons who overemphasize the bodily symptoms of MS. In social relations, people with MS “feel more ill” as the consequence of stigma (Grytten and Måseide 2006).

Empowerment (Freire 1970) is a proper term to use in connection with the work in the study circles, but the support is not only directed from the health care professionals and study circle leaders to the patients but more importantly, from the persons with MS to each other, as we can see in the focus interview described above. One of the most significant effects that can be achieved in the circles is that crucial information about the perceived impact of the disease will spread to the health care professionals involved. This can be of great importance for future MS care, but this subject is not further studied or evaluated in this article.

Conclusion

Studies support the existence of distinct “disease worlds” based on chronic disease states (Thorne et al 2004). The specific MS study circle is thus an important concept that should be developed further because it provides information, increases coping, compliance, and motivation to undergo therapy. We believe that such pedagogic interventions can improve strategies in daily living and increase quality of life. Recent research suggests that improvement in quality of life can improve the natural course of the disease (Nortvedt et al 2001a). This highlights the importance of pedagogic efforts such as the study circle.

Practical implications

We have noticed that when study circles are permanently established and function well, work at the MS clinic is substantially facilitated. The time spent in this pedagogic work is time well invested because the patient will be better informed about their medical condition and will also have another arena in which they can deal with psychological and existential problems. This observation, together with the satisfaction that the patients express, will certainly increase the spread of this particular form of study circle to other parts of Sweden.

Patient/personal identity numbers have been removed or disguised so the patients described are not identifiable and cannot be identified through medical history details.

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