Self-help groups in Belgium: their place in the care network

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Abstract

Many academics consider self-help groups as an important factor in the resurgence of democratic life in society. The academic debate on self-help groups however, neglects the contextual connection of these groups. The article is based on a two-fold piece of research in Belgium on self-help groups. The image and the position of self-help groups for breast cancer patients is examined. On the one hand, a quantitative network analysis shows the place of the group within the official medical health care network. On the other, this analysis is complemented by qualitative interviews on breast cancer patients. From these two analyses, some marked differences are detected between the positive image of self-help groups in academic literature and the personal views of their target group (breast cancer patients).

Keywords: self-help groups, breast cancer, network analysis, qualitative research

Introduction

Questioning the image of self-help groups is risky. From the moment they became widespread all over the world in the 60s and 70s, they have been praised for hundreds of reasons. Especially in the United States, self-help groups have been regarded in a most positive way. The European experience, however, is somewhat different. This article focuses on the image of self-help groups for breast cancer patients in Belgium. The aim of the research is two-fold. We first focus on the image of self-help groups in the medical world. For this we use a network analysis of care facilities in a
Belgian province. Secondly, the article reports on a qualitative research project among breast cancer patients. These patients were interviewed on their past experiences with self-help groups for breast cancer. As will be argued, the image of self-help groups is not always consistent with the highly-praised functions we found in the literature.

**Literature review**

Self-help groups have existed for a long time. The first such group, Alcoholics Anonymous, started in 1935. Nowadays, there are self-help groups for almost everything (Newton 1984: 28). At the end of the 70s, the total number of self-help groups in the United States was estimated to be more than 500,000 (Arntson and Droge 1987).

Over the years, the image of self-help has changed. In the 60s, self-help groups were viewed as strange subcultures of deviants, and were stigmatised. A decade later, anti-professionalism was the pre-eminent feature. Self-help was considered a democratic alternative to the strongly specialised and highly technological health care. Nowadays, it is agreed that self-help groups are not necessarily strictly anti-professional, neither are they a substitute for the existing health care system (Stevens and Matthijs 1994: 11–12). Self-help groups may be supplementary to professional assistance. In addition, they may contribute to the growing questioning of medical practice: ‘they are groups which place a value on experiential knowledge, thus implicitly challenging the authority of professional health care workers to define what it is to have a particular condition and how it should be managed’ (Kelleher 1994: 111).

Self-help groups gather together people with a similar problem in order to help them by a personal approach, preferably to solve the problem, and, where that is impossible, to teach them how to live with their constraints. This comes close to the definition of self-help groups used by the ‘Meeting Point Self-help Groups’ in Belgium: a self-help group is ‘a group of people who experience or have experienced something similar (a life-threatening problem or a problem that threatens the quality of life) and in consideration of which they feel powerless, and decide to do something about it together’ (De Wilde 1996: 118).

Although self-help groups are praised by several authors for their positive effects on their members, a few authors warn of the tensions within the very concept of self-help. Gareth Williams, for example, describes the Janus-faced nature of self-help groups. On the one hand, he sees a collectivist version of self-help. This implies ‘a more or less formal system of looking after others in the community or workplace’ (Williams 1989: 136). Mutual aid or reciprocity are the key words. On the other hand, there is an individualistic approach to self-help. Important concepts are independence or self-reliance. Self-help groups seem to suffer from ideological duality: ‘in one
guise it [self-help groups] celebrates individual freedom against a corporatist state, however illusory or limited this freedom may be in practice; it does articulate a collective defence of communal resources, however paltry and dehumanizing these may be in reality’ (Williams 1989: 138). In order to understand modern self-help groups, Williams believes it is necessary to recognise these different historical origins. The Janus-faced character of self-help groups has led to different dichotomous classifications. Williams names individualistic and collectivistic dimensions; Katz and Bender distinguish between inner-focused and outer-focused self-help groups. The inner-focused give emotional and social support, opportunities for personal growth and so on. The outer-focused are mainly devoted to changing legislation or social policy (Katz and Bender 1976: 39). The latter function as pressure groups. Although most groups are both inner and outer-directed, they do emphasise a particular function. The network approach that will be discussed later, makes no distinction between the two types whereas the qualitative research focuses on the inner-directed ones.

Predominantly, inner-directed self-help groups fulfil two main functions. On the one hand, there is an informative aspect, on the other, an emotional aspect. The main objectives of such self-help groups are seen as providing information and the means of learning how to deal with emotional and psychological stress (Stevens and Matthijs 1994: 34). Next to information and contacts between fellow-sufferers, Gielen sees other goals: promoting patients’ interests and influencing care services (Gielen 1996: 146). Other recurring aspects are organising meetings of fellow-sufferers; provision of understandable, up-to-date information; offering of practical help; organisation of social contacts, helping people out of their isolation; representation of the interests of the members; pursuit of good co-operation with social workers and the maintenance of contacts with other organisations. Self-help groups are not only beneficial for the individual, but they are also important for community development, citizen activism and individual empowerment (Ben-Ari 1998: 132). Many academics consider them as social movement organisations (Kelleher 1994). They combine environmental change and individual empowerment (Chesler and Chesney 1995: 299). Therefore, self-help groups are seen to play an important role in the resurgence of democratic life in society (Gartner and Riessman 1998, Riessman 1997).

The informative aspect of self-help groups consists in giving the members of the group adequate information on their common problem. Self-help groups are primarily a source of information: ‘the family and self-help groups ... are the main building blocks for supporting people with chronic illness, and this caring involvement extends throughout the experience of living with chronic illness’ (Anderson 1992: 265). Self-help groups can count on a broad public acceptance. This means they reach a large part of their target group (Saelens 1994: 3). According to Satterwhite and colleagues, meetings where information is provided about cancer, or how to deal with
the psychosocial impact, are appreciated the most by the members (Satterwhite et al. 1993: 240–2). Research conducted by Spaniol and Jung in 1983 pointed out that many patients attach great importance to the self-help group: ‘one-third of the sample stated that the self-help group was their most important source of support . . . similarly, self-help groups were cited to a greater degree than mental health professionals as the most helpful for learning information’ (Cited in: Biegel et al. 1991: 191).

The emotional support of the group on the other hand, is depicted as helping the members to put their problem into perspective. The stigma is alleviated. Furthermore, the members learn ‘to build up a new way of everyday life through being involved in a wide range of group activities’ (Robinson 1985: 111). Self-help groups are considered an important source of social and emotional support. They offer their members the chance to meet and learn from each other, being a significant source of information and advice (Branckaerts and Richardson 1992: 363–4). The contacts between fellow sufferers are evaluated positively. It is a form of personal contact between the patient and one or more other patients or ex-patients with the same disease (van den Borne et al. 1992: 369). Research by Van Den Borne and Pruyn indicates that contact with fellow breast cancer patients is able to reduce insecurity about help possibilities and negative feelings, such as depression, fear and psychological complaints, and to increase the feeling of self-esteem (van den Borne and Pruyn 1985). Self-help groups are considered to be less threatening than comparable professional treatments. The members recognise and respect the lack of skills in using techniques like confrontation (Knight 1980: 63).

The informative-emotional distinction is confirmed by a study of Kelleher’s. He examined eight self-help groups for people with diabetes. The leaders of these groups made clear that the focus of interaction has to be ‘a sharing of experience mixed in with the giving of practical advice’ (Kelleher 1990: 68).

The literature commonly talks about self-help groups in a positive way, with respect both to the informative and the emotional aspects. It has been claimed (Anderson 1992) that, next to family, self-help groups are the most important pillars for the chronically ill. They are considered as two complementary sources. In relation to cancer in general and breast cancer in particular, self-help groups fulfil an important role in the care network around the patient.

The aims of the study reported here were two-fold. First, we investigated the care network for breast cancer patients in a Belgian province. The network analysis of the data gathered gives an idea of the image and the place of self-help groups in the care network as a whole. Secondly, we supplemented these data with a qualitative research component in order to get a picture of the patient’s view on self-help groups for breast cancer. In our analysis, we examine the place of self-help groups in the medical world vis a vis the views of (former) breast cancer patients.
Methods

Quantitative network analysis

The sample: The quantitative part of the research aimed to detect where self-help groups stood in the care network of breast cancer patients. In 1995, explorative research was conducted at the Department of Political and Social Sciences of the University of Antwerp on the existing care facilities for breast cancer patients. The objective was to explore the size, structure and dynamics of the existing care network for breast cancer patients in Antwerp, with particular emphasis on the non-medical care for breast cancer patients. This included all care activities whether psychosocial or material in orientation, provided by professionals or volunteers.

The exploration of the care network started with a small number of care organisations that were known to help breast cancer patients, building up to a network of 57 different care organisations. The information was obtained by interviewing field experts and reviewing written or digitised sources. The representative of small organisations such as self-help groups was usually the person in charge of the organisation. The delegate of larger organisations, such as hospitals or other health service facilities, was often the head of the social services department. In addition to a number of general identification questions (address, foundation, field of activity, opening hours) and questions about the target group of the organisation, the questionnaire also contained questions on the actual services (type, contents, goals, bottlenecks) and the resources and people the organisation had at its disposal. Further, there were questions included about the network ties the organisation had with other organisations concerning services to breast cancer patients. These network ties imply referral relations as well as co-operative ones. Organisations are referrers when they pass patients on to another organisation. Co-operation signifies that more than one organisation is simultaneously involved in the care process of one patient.

Network analysis

The network analysis at dyad level analyses the relations between the network actors. To conduct this analysis, a second database was created founded on the original selection of organisations. This second database did not have the original 57 organisations as observation units, but the 237 network relations between care providers. These 237 existing network relations are connected between dyads of organisations, which can be divided into three types. In total, 109 input relations were registered (actor gets a patient from another organisation), plus 137 output relations (actor refers a patient to another organisation) and 108 co-operative ties (actor works together with another organisation). This brings the total amount of different relations, subdivided into type, to 354 (108, 109 and 137). A network connection between a dyad of actors could be an input relation, an
output relation, a co-operative relation or a combination of two or three of these. This explains why there was a registration of 354 different network relations and only 237 dyads.

The density of a network in this kind of analysis reflects the proportion of existing network relations with regard to possible network relations (Scott 1991: 66–79, Wasserman and Faust 1994: 92–7). Some organisations (nine out of 57) in our network did not mention any network references. Most (48) mentioned at least one other organisation they referred to, got patients from, or co-operated with. This brings the total amount of possible network relations between the 57 organisations to 2736. Because there are only 237 existing network connections between couples of actors, the care network for breast cancer patients has a density of 8.7 per cent.

Another central concept in network analysis is that of betweenness². This measures the extent to which a particular point lies ‘between’ the various other points in the network. Scott defines betweenness as: ‘the extent to which a particular point lies “between” the various other points in the graph. (...) The betweenness of a point measures the extent to which an agent can play the part of a “broker” or “gatekeeper” with a potential for control over others’ (Scott 1991: 89–90). If an organisation in the care network has a high degree of betweenness, it indicates that it plays a central role in the network. All measures of betweenness were calculated with the network computer programme UCINET (Borgatti et al. 1992).

**Qualitative research**

The sample: A qualitative research method was used to study the different care needs of breast cancer patients. In order to get a full picture of the role self-help groups play in breast cancer treatment and recovery, a sample was constructed, based on different stages in the development of the disease. This procedure was necessary to prevent recall problems during the interviews. Qualitative research can give valuable insights if the data gathered during the interviews are valid and reliable. Since our research aimed to cover both the hospitalisation period and the period of recuperation³ after a breast cancer operation, a double sample was necessary. A first group of women had had breast surgery in the last months before the research (breast conserving surgery or mastectomy). A second group had been cancer free for the last five years and was contacted mainly so as to gain insight to the recovery and recuperation period.

Seventeen women were interviewed. The sample size in qualitative research is dependent on the quality and the saturation of the data and not on the number of participants (Nelson 1996). With 17 women in the sample the saturation requirement was met. No additional information was obtained by further interviewing. The final sample consisted of nine women who had undergone recent surgery, and eight women who had been cancer free for more than five years. In the first group, five women had had a breast conserving operation and four a mastectomy. Among the women who had

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been cancer free for more than five years, three had had a breast conserving operation while five had had a mastectomy. Participants’ ages ranged from 35 to 83 years, with a median age of 59. Most women were married (11), three were unmarried, two were divorced and one was a widow. The women’s educational levels ranged from none at all (one woman) to a university degree. The median educational level was secondary school.

Interview process
The research procedure was in two stages. First, a written questionnaire was sent out to 159 women who had been selected on the basis of their medical records from the Imelda hospital in Bonheiden, Belgium. The questionnaire introduced the research project. It consisted mainly of the RAND36 (Hays et al. 1993, Ware and Sherbourne 1992) quality of life instrument. In addition to this, several socio-economic questions were asked to check for the psychometric properties of the scale in our sample. The questionnaire asked the women if they were willing to participate in a face-to-face interview.

The written questionnaire was returned by 133 women (giving a response rate of 83 per cent). From the subset of women who agreed to co-operate in an interview, a second sample was drawn according to the criteria mentioned earlier (recent surgery or cancer free for five years). These women were contacted by telephone and asked to make an appointment for an in-depth interview on their breast cancer experiences and their experience and satisfaction with breast cancer care. None of the contacted women refused to participate. The interview took place with a semi-structured questionnaire based on a few closed questions and an elaborate topic list. Because the self-help literature underlines the emotional as well as the informative aspect of self-help groups, both were included in the questionnaire. During the interviews the women were asked to elaborate on responses in order to enhance the quality of the gathered data. In this fashion, vague answers could be reduced maximally. On average an interview lasted between one and two hours. All interviews were literally transcribed before analysis. The qualitative software package Atlas/ti was used to analyse the interviews.

Results

Quantitative network analysis
It is hypothesised that self-help groups play a central role in the care network for breast cancer patients. If this hypothesis is correct, it should be confirmed in the patterns of referral at relational level. This can be detected by comparing the pattern of observed relations with the pattern of expected relations, given the number of possible relations. The relations are considered separately on the basis of input, output and co-operation.
When we look at the output references of care services by self-help groups in terms of percentages, self-help groups were most frequently mentioned as organisations to which hospitals (47 per cent) and other self-help groups (35 per cent) referred patients. In the third place there were general cancer organisations (15 per cent). Health services and home care services hardly appeared. We can compare this to the input references of self-help groups. These relations show the reverse picture, whether or not self-help groups mentioned hospitals and other self-help groups to the same degree. Both series of percentages are shown in Table 1.

Table 1: Referral to self-help groups by output and input references (row percentages and (frequencies))

<table>
<thead>
<tr>
<th></th>
<th>Hospital</th>
<th>Self-help group</th>
<th>Gen. cancer organisation</th>
<th>Health service</th>
<th>Home care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Output by self-help groups (N = 66)</td>
<td>47 (31)</td>
<td>35 (23)</td>
<td>15 (10)</td>
<td>2 (1)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Input by self-help groups (N = 55)</td>
<td>58 (32)</td>
<td>17 (9)</td>
<td>7 (4)</td>
<td>16 (9)</td>
<td>2 (1)</td>
</tr>
</tbody>
</table>

The input relations mainly reflect the same results. Self-help groups most frequently mentioned hospitals as the primary source of breast cancer patients (58 per cent). There were also internal referrals by other self-help groups (17 per cent) and referrals by health services (16 per cent). Although hospitals remained in the first place, there was a larger input-output gap with other self-help groups. Moreover, there seemed to be a considerable dissimilarity concerning health services. A fair number of self-help groups considered health services as an important source of possible members, whereas the health services did not think of themselves as possible output organisations. There is no explanation for this difference.

To have a complete picture of the direct relation network of self-help groups we need to consider the different co-operative relations of the organisations. If we look at the network of co-operative relations as viewed by the self-help groups, again hospitals play a key role. More than 70 per cent of the co-operative relations mentioned by self-help groups were ties with one or another hospital. To a lesser degree they indicated co-operation with other self-help groups and health services. General cancer organisations or home care initiatives were not mentioned (see Table 2).

The reversed relations show that both hospitals and other self-help groups mentioned self-help groups as a co-operative partner in taking care of breast cancer patients. General cancer organisations and home care services did not mention any self-help group they worked with. Although numbers are...
fairly low, there is evident a second inequality between self-help groups and health services. Self-help groups were more likely to mention health services than vice versa.

Figure 1 provides a schematic overview of the input, output and co-operative relations, in accordance with the answers of self-help groups. Internal referrals (input and output) between different self-help groups seem to be of great importance. Hospitals and self-help groups are strongly connected. They co-operate and refer patients to self-help groups.

Table 2: Referral to self-help groups by co-operative references (row percentages and frequencies)

<table>
<thead>
<tr>
<th>Co-operation mentioned by self-help groups</th>
<th>Hospital</th>
<th>Self-help group</th>
<th>Health service</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 31</td>
<td>71 (22)</td>
<td>19 (6)</td>
<td>10 (3)</td>
</tr>
<tr>
<td>Co-operation with self-help groups</td>
<td>N = 31</td>
<td>78 (24)</td>
<td>19 (6)</td>
</tr>
</tbody>
</table>

Figure 1: Network relations of self-help groups, relation type in terms of percentage

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The central role of self-help groups in the breast cancer care network can be further elaborated by looking at the measures of betweenness of the different types of care. To get a view on the distribution of the degree of centrality in the breast cancer care network, we divided the measures of centrality into three equal classes (Table 3).

Table 3: Betweenness and type of care

<table>
<thead>
<tr>
<th></th>
<th>Hospital N=24</th>
<th>Self-help group N=16</th>
<th>Gen. Cancer Organisation N=3</th>
<th>Health Service N=7</th>
<th>Home Care N=7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>24 (6)</td>
<td>25 (4)</td>
<td>67 (2)</td>
<td>57 (4)</td>
<td>43 (3)</td>
</tr>
<tr>
<td>Medium</td>
<td>38 (9)</td>
<td>31 (5)</td>
<td>0 (0)</td>
<td>29 (2)</td>
<td>43 (3)</td>
</tr>
<tr>
<td>High</td>
<td>38 (9)</td>
<td>44 (7)</td>
<td>33 (1)</td>
<td>14 (1)</td>
<td>14 (1)</td>
</tr>
</tbody>
</table>

The result confirms our previous analysis: self-help groups are central in the breast care network. Almost half of the self-help groups (44 per cent) in the sample had the highest degree of betweenness, indicating they were central in the network. Furthermore, hospitals played an important role. This is no surprise since they were responsible for the major interventions in the breast cancer trajectory. The other types of care were less important in the breast cancer network.

Qualitative research

Self-help groups mainly operate in two stages of the breast cancer trajectory. Before medical surgery or hospitalisation, no self-help groups are involved. They enter during the hospitalisation period when paying a visit to the patient. During this visit self-help groups mainly provide information. The emotional support from the groups usually comes in the period of recuperation. During this time, breast cancer groups organise group sessions, and some of them have private conversations with the patients.

Perception of the informative function of self-help groups

During their stay in the hospital, breast cancer patients usually received a visit from a representative of a self-help group. Often the visitor was a patient who had been cancer free for a long time. She told of her own experiences with breast cancer and gave practical information about prosthesis, adjusted lingerie, useful addresses and so on.

They talked about their own experiences, those two ladies. But also about temporary prosthesis, about the real prosthesis, showed pictures, showed their own prosthesis, . . . gave a list of lingerie shops and so on, a little book telling what you can and cannot do with your arm and so on. That
is a shortcoming, because that is not said by the nursing staff, by doctors and sorts (Annie).

The representative herself was living proof of someone who had had breast surgery and had got on with her life, that she could look good and normal. She was considered to be a role model for other patients. This is a form of upward comparison, where people in a crisis situation pattern themselves on people in a comparable situation who are doing well. The women were invited for later sessions of the self-help group concerned.

Yes, that self-help group, yes, it was interesting to hear what, well, in connection with prostheses, that was the first time that I . . . yes, actually you don’t know that, . . . that I got in touch with that, that stuff and yes, for practical matters, yes. Because you have to know something about the practical side. You have to move on with it . . . to look a bit decent, right (Ria).

All respondents evaluated the hospital visit as a positive thing. Especially stressed and appreciated was the informative aspect of the visit. Concerning the delivery of information, self-help groups scored very well with their hospital visit.

Perception of the emotional function of self-help groups
When the women were interviewed about later support by self-help groups, the comments were rather negative. Only three of our respondents came to sessions of the self-help group. Most women said they had received enough support within their own environment:

Actually I could talk very well about it to my sister. That’s true, I didn’t think I had to explain it all over again to someone else, someone strange (Ria).

Often self-help groups were seen as a substitute for disappearing social ties, family life, etc. (Bakker and Mattieu 1983: 164, Banks 1997: 34, Kessler et al. 1997: 45). Apparently there is less need for self-help groups if there is a good relationship with the partner and/or other people.

Others just felt no need for participating in a self-help group.

Someone did come by when I was still in the hospital and she gave me her card. It is lying here somewhere, but I don’t remember where. And she came to talk about it and said so and so, because the lady had had the same thing and she wanted to help people and talk about it and things like that. And she said that if I had revolting thoughts or something, or I couldn’t pull myself together, I could always go to her. If I called her I could always go over, or she would come to my place to talk about it, but I never felt any need for that (Mia).
A third major reason for not wanting to participate in a self-help group was that the women wanted to leave the cancer behind them. Women who wanted to move on with their lives, thought they would feel obstructed by attending a self-help group (Luker et al. 1996: 494). This relates to problems of identity. Self-help groups help people not to feel different from other people. In reality, the danger exists that self-help groups affirm someone’s identity as a sufferer from breast cancer. Zola also warns of the difficulties people with chronic illness and disability experience if they are labelled as such (Zola 1993).

Among the three respondents who did go to a group session of a self-help group, the same negative reactions were found, although the reasons for being negative were different from those of the other women. In the first place, there was some kind of age gap. One of the younger respondents felt ill at ease in the group session because of the difference in age between her and the other participants:

I do want to go back one time ... well ... I don’t know ... the last time, I did not return like I ... I felt worse than before. And it was all, how to say this ... women from an older generation. I felt really uncomfortable with that. If I would meet some younger women there to chat with, I would consider returning. (Magda).

A second reason for not returning to the group session originated in a different kind of comparison. Some of the women experienced a gap in severity between them and the group members. The discussion in the group was experienced as a therapy for the worst cases:

I think there are others that are worse off than me ... I think these groups are for women who can’t talk about their problems at home (Ria).

The type of conversation in the group sessions was a final reason for not returning any more. Some women did not like the informal ways of conversation during the sessions:

I did go to a meeting once. The first meeting of the group. But afterwards ... just once ... I do not like these coffee klatsches (Helena).

Some women considered the group sessions as a waste of time. The interviewees gave similar reasons for not participating when they were there. The women who did go to a self-help session went with high hopes and were fairly disappointed.

Need for self-help groups before hospitalisation

Looking positively at the informational aspect of self-help groups during hospitalisation, there could be a possible new role at the beginning of the
breast cancer trajectory. From our interviews, we learned that the moment of diagnosis was a painful bottleneck. Often, things went wrong when a specialist informed the woman of the diagnosis. For example, the woman was alone when she got the news. A few women even reported that the doctor cold-bloodedly had his say and left immediately.

He [the specialist] enters my room with a nurse and says: ‘Yes madam, you are alone there, aren’t you? Alone in your room. Yes madam, you can go home now. You will return next week for a mastectomy. You are a strong woman. I can see that. I can see you can cope with this situation.’ He says it like that, in those words. What you feel . . . I can’t describe my feelings at that moment. And the doctor left, just like that. That’s it. That was not human (Ria).

There was a problem of support at moments of diagnosis. The same finding was reported by Waltz. He presumes there is little acknowledgement of this problem by specialists (Waltz 1992). Several interviewees spoke about a lack of personal support in which time is made for the emotional state of the patient. Several women wanted some sort of support where someone who had had the same experience was available to answer questions.

More information from someone who has had breast cancer. The specialist and my general practitioner are giving information . . . but they don’t live with this. They cut away a breast but they don’t realise how it feels to lose a breast. I think it would be an advantage to talk woman to woman (Nicole).

Discussion

The quantitative data indicated that self-help groups take a central place in the care network for breast cancer patients. This central position appeared most obviously in the output relations, i.e. in the referral of breast cancer patients from different care organisations to self-help groups. The analysis showed that breast cancer patients in this care network eventually were relatively more often referred to a self-help group than to other organisations for breast cancer patients. In the first instance, this referral was made by a hospital and/or internally, by another self-help group. The existing co-operation in providing care for breast cancer patients was most intense between hospitals and self-help groups.

The traditional organisations reappeared in the network analysis by relation type, namely in the analysis of input relations. Breast cancer patients seemed to have a greater chance of being referred by the more traditional organisations, such as health services and hospitals. The quantitative network analysis seemed to confirm the central image of self-help groups.
The interviews reveal a dual picture. The visit of a self-help group representative during hospitalisation was evaluated positively. The women were satisfied with the practical information they received during their hospitalisation. Thus the informative aspect of self-help groups scored very well. But meetings of self-help groups were viewed rather negatively.

We can conclude that there is a gap between the informative and emotional aspects of self-help groups. They are appreciated for the first aspect, but the consumer seems to be less happy with the second. A first possible explanation is provided by Anderson who sees families and self-help groups as two complementary sources. He considers a self-help group mainly as a source of information (Anderson 1992: 265). We can say there is a conceptual distinction between the informative and emotional functions of self-help groups.

Second, breast cancer groups would seem to assume a special position. The negative functions of labelling, alluded to by Zola (Zola 1993), could be more apparent for breast cancer because of the nature of breast cancer itself. Unlike other diseases, breast cancer has little or no implications for daily life after a patient has recovered. Besides the use of a prosthesis in the case of a mastectomy and the follow-up researches, breast cancer has little or no practical influence on a woman’s life. Therefore, attendance at group sessions might contribute to a negative labelling process. Even though self-help groups try to avoid these consequences, they could reinforce the process.

A third explanation for the gap between the informative and the emotional functions of self-help groups, could lie in their image as presented to the outside world. The phenomenon has travelled from the United States to Europe via the medium of mass communication. Many television films or soaps have constructed the image of a self-help group as people sitting in a circle, complaining and chatting for hours and hours. There is even a new Dutch idiom based on this image. If someone eagerly wants to say something, he is welcomed with the words ‘throw it into the group’. The mass media persist in portraying self-help groups in a highly caricatured way. In 1997, a radio commercial for a certain brand of chips, that extols the diversity of that brand, illustrates this caricatured image. The commercial uses the voice of a man sitting in a self-help group session for addicts of a certain brand of potato chips. The conversation goes as follows: ‘Hello, my name is Marc and I am no longer addicted to chips X (warm applause follows in the background). So, this will be the last session I will see you at. But don’t be afraid, I might see you next week in the self-help group for addicts of chips Y’.

When talking about information and practical tips, all the women were extremely positive in their judgements. The moment the subject moved to later guidance by the self-help group, their judgement changed. Nevertheless, the need to talk to women who had experienced the same thing was repeatedly mentioned. In other words, the need for contacts between fellow-sufferers:
If they would have had people who had the same thing, if they could tell something out of their own experience. If I had someone like that, well yes, I would have been very happy about it (Magda).

This is remarkable, because most self-help groups organise contacts between fellow-sufferers. Hearing the word ‘self-help group’ reminds people of group meetings where people come to sing songs of lamentation:

A self-help group, that is like sitting in a group and complaining aloud . . . I don’t like that (Monique).

The finding that not all patients felt attracted to self-help groups possibly explains the attitude of rejection towards self-help groups. For a number of people participation in a group is felt as threatening (Biegel et al. 1991: 89). A lot of women, therefore, do wish to have personal contacts with fellow sufferers, but only with one at a time. There is obviously a need for individual conversations, dyadic contacts between fellow-patients (one-on-one), besides contacts in larger self-help groups.

However, if we look at the different activities of self-help groups, there is more than mere group talks. Individual contacts and recreational activities also form a part. Contact between fellow-sufferers is not always experienced within the group. Often it takes the form of face-to-face contacts or telephone calls. This is often missing in the image of self-help groups. For a number of people it is not socially acceptable to join a self-help group (Newton 1984: 30).

Conclusion

In Belgium there are many self-help groups that are highly involved in the official care network, network analysis illustrating their central position. They score high on input relations and output references. Moreover, self-help groups have a high degree of betweenness. In that respect, they occupy an important and legitimised position in this world. If we look at the target group however, a different picture emerges. The breast cancer patient is not always positive in her judgement. In other words, the so-called new movement of self-help groups is not supported from the grass roots. Concerning the informative aspect during hospitalisation, self-help groups score very well. They really respond to a concrete need. Group sessions at a later stage do not have a positive image. On the whole, they are considered to be useless or just as sources for chat.

Why is there such a big difference? The most important explanation for this cultural difference seems to be the general image self-help groups possess in Belgium. The classic image of a coffee klatsches is repeated over and over again. Self-help groups have earned their place in the network of

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breast cancer care. They could get a stronger role in supporting patients emotionally if they were to succeed in changing the prevalent simplified image. A possible answer could be an increase in personal support, the face-to-face conversations. The respondents in our research would seem to have benefited from a personal approach.

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Notes

1 After examining the National Ankylosing Spondylitis Society (a form of chronic arthritis that principally affects the spine), he finds the individualistic version dominant over the collective one. This makes it difficult for the society to respond in a meaningful way to social aspects of disablement (Williams 1989).

2 The measure of betweenness for an actor is calculated as the sum of all estimated probabilities over all pairs of actors (not including the \(i\)th actor):

\[
C_B(n_i) = \sum_{j<k} g_{jk}(n_i)/g_{jk}
\]

The measure has a minimum value of zero and reaches its maximum at \((g-1)(g-2)/2\) (Wasserman and Faust 1994: 190).

3 Recuperation covers the period after hospitalisation. It includes recovery and, if necessary, chemotherapy, breast reconstruction and so on.

4 The RAND-36 scale was tested on different patient groups (Kurtin et al. 1992, Mc Horney et al. 1993, Nerenz et al. 1992). In order to check whether or not the instrument reacts differently on some dimensions, both socio-economic and medical variables are used to test the instrument within different subgroups within the larger sample.

References


Self-help groups in Belgium


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