

SELF-HELP GROUPS FOR PATIENT SUPPORT

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I. INTRODUCTION

The roots of self-help can be tracked back to ancient times. Even according to biblical doctrines, it was a moral duty to help oneself and others in need (Kéri, 2011). Self-help patient groups were created on the basis of the needs of those with the same pathology or problem; for example, mutually helping each other by sharing their experiences. Among its members there were stigmatized or deviant people, or followers of alternative lifestyles, as well as voluntary associations of people with chronic diseases (Csepeli, 2001; Jacobs & Goodman, 1989; Katz, 1993; Katz & Bender, 1976). The ways these groups are operating are very similar, they are organized along particular diseases and their aim is usually to promote healing; using group-cohesion, strengthening the sense of belonging, sharing personal and other experiences (Katz, 1993; Katz & Bender 1976). Several studies describe that participation in patient groups relieves anxiety caused by diagnosis, by examinations or by therapies, and can improve adaptation to diseases (Campbell et al., 2004; Meyer & Mark, 1999; Newell et al., 2002; Poole et al., 2001).

Patient groups are characterized by advocating the rights of patients, and/or educating patients. Education facilitates the knowledge of the disease and the patient's path, can improve communication skills, develop appropriate coping mechanisms and promote desirable psychological well-being, all of which can significantly increase persistence and adherence (Cain et al., 1986; Docherty, 2004).

Meetings of patient self-help groups may be based on different approaches, and the gatherings may differ both in nature and in dynamics. The meeting can take place in person or online, can be open or private, ad hoc or regular, and can be organized thematically, led by experts. The main goals are emotional support, sharing similar experiences of fears and experiences, increasing the individual resources of each patient, reducing anxiety, expanding coping strategies, helping rehabilitation, and enhancing social support. It is typical in the open-attending group that the members are not permanently present, the meetings are incidental. The permanent membership of the private group increases the experience of belonging.

The largest number of patient support groups were organized for cancer patients with significant distress in order to strengthen the patient's sense of control, the pa-

tient's belief in his or her autonomy and to help them make decisions by having better access to information (Anderson & Funnell, 2005; Hibbard et al., 2004; Newell et al., 2002).

Self-help group meetings are characterized by thematic regular meetings, exchange of experiences, psychosocial support, organized and led by experts (such as health psychologists) (Gutgsell et al., 2013; Teo et al., 2019).

2. SELF-HELP PATIENT GROUPS OPERATING IN HUNGARY

In Hungary, the roots of self-help activities go back to the period before the Second World War, as some self-help groups were formed at that time, but they were quickly disbanded due to the political and social situation at the time. In postwar times, the first self-help group organized by alcoholics began to operate in 1955 with the aim of strengthening members and overcoming harmful dependence or counter social exclusion. This self-help group became the early predecessor of today's organizations of alcoholics (Gerevich, 1983). The real change was brought about by the previously mentioned Health Preservation Program, which was drawn up in 1987, and then the Law on the Right of Association, which came into force in 1989, made it possible to organize self-help groups ("Egyesületi jogról szóló törvény"; Kéri, 2011).

The Hungarian Anti-Cancer League was founded in 1990 to help cancer patients. It has considered health promotion as its main task and has drawn attention to the importance of early detection of the disease, participation in screening tests and self-examinations. They regularly provide rehabilitation-club meetings to people with the disease, and they also provide legal and psychological support to both patients and relatives. Over the years, more and more self-help groups have been formed along the lines of various diseases or disabilities, and they have been working successfully ever since. Examples include "By Heart" National Patient Association („SZÍV SN Országos Beteggyesület”), the Stroke Info Foundation („Strokeinfó Alapítvány”), the National Association of People with Rare and Congenital Disorders („RIROSZ – a Ritka és Veszélyes Rendellenességgel élők Országos Szövetsége”), or the “Mauve Flower Association” „Mályvavirág Egyesület”, which helps women with cervical and ovarian cancers.

Self-help groups and organizations have been formed in Hungary to help women with breast cancer, similarly to many countries around the world (for example in the USA, Netherlands, Germany and Poland). The “Bridge of Health Association against Breast Cancer” („Egészség Hídja Összefogás a Mellrák Ellen”) is about 17 years old; the “Pink Bolero Self-Help Association against Breast Cancer” („Pink Bolero Önszolgáltató Egyesület a Mellrák Ellen”) was founded 10 years ago; and the “My Tomorrow Association – Together against Cancer” („Holnapom Egyesület – együtt a rák ellen”) was organized in the city of Debrecen. There are several groups active on online platforms, such as the “Breast Cancer Information Association” founded about six years ago

(„Mellrákinfo Egyesület”), the “Do It for Yourself” („Tegyel Magadért”) or the “Breast-Protect” („Mell-Véd”) self-help groups. These patient helper groups usually form closed meetings, making them suitable for truly confidential conversations.

Self-help patient groups play an important role in the lives of diagnosed patients and their relatives in Hungary, as well as in other countries of the world. These regular appointments and programs help to adapt to the disease, relieve anxiety and fears, while increasing the experience of belonging. Asymptomatic patients often take on a voluntary helper role, so the experiences they share with their newly diagnosed peers are truly credible.

3. PINK BOLERO: INTRODUCING A SELF-HELP GROUP FOR WOMEN WITH BREAST CANCER IN HUNGARY

In 2011, one of the leading oncologists in the Oncology Center of Semmelweis University (prof. Dr. Magdolna Dank), the health psychologist of the department (the author of this paper) and a recovered person who has been symptom-free for several years (Aranka Pataki) founded the “Pink Bolero Self-Help Association against Breast Cancer”. The aim of the group was to provide space for the meetings of patients who are experiencing similar difficulties. The Pink Bolero Self-help Association's self-help group operates as a closed group, but it also welcomes hospitalized inpatients who are interested in the lectures advertised. In group meetings, the health psychologist's task is mainly to help with coherent conversations, to adapt to the topic, and to strengthen group cohesion. On the other hand, her task is to apply various psychosocial methods, to lead relaxation and meditation, as well as to conduct art therapy tasks to relieve fears and anxiety. She actively assists in education, interventions and support. The oncologist herself participates in these informal discussions, this way members can get answers to their questions that they would not be able to ask due to the lack of time in formal consulting hours. With her help, we can also invite other specialists to our group meetings. The role of the recovered founding member is also very important, since she is able to understand the others as a fellow patient, as she has experienced the side effects of various therapies, so she can help competently to alleviate them, and her knowledge of the disease is credible for those who turn to her. Last but not least, her recovery, her years of being free of symptoms and healthy lifestyle can give a positive model and motivation to others. At group meetings, members can experience the acceptance and supportive power of the community – they discuss and reframe individual fears, doubts, or clear up misinformation. An important role in the life of the group is that members can share and shape their own patterns of coping mechanisms.

3.1. HOW THE PINK BOLERO SELF-HELP GROUP WORKS: GROUP PROCESSES

The Oncology Centre hosted the Association for biweekly group sessions. The members (the women affected by the disease) initially joined from among the patients of the university clinic, and then, as soon as the “news” of the group reached other institutions, the participants started coming from various parts of the country, significantly expanding the group membership.

The meetings are organized around the issues of greatest interest to those affected and related to cancer, but the main goal is always to come together joyfully. Group meetings are usually thematic, and the topics are planned in advance by the members at the annual general meeting. According to their ideas, various specialists – such as oncologists, surgeons, radiologists, physicians – as well as other specialists such as dietitians, physiotherapists or stylists are invited. They help, among other things, to choose and wear wigs and replacements correctly, when they are invited to informal discussions. At these meetings, those concerned are free to ask questions that they cannot at the doctor's appointments due to the lack of time. The most important issue is to explore the background of the disease processes and the nature and significance of the different therapies, which can lead to better acceptance. Art therapy, movement therapy and relaxation or meditation exercises are also included in the topics. Art therapy sessions always include an occupation chosen by the members, whether it is mandala painting, beading or making jewelry, but listening to music and discussing various musical works is also popular. Movement therapy is being practiced every time and is always led by a specialist. The members are very fond of tai-chi exercises, these slow movements strengthen balance, stretching helps relieve stress, and under the guidance of a physiotherapist members can learn and practice rehabilitation exercises before and after surgery. Two to three times a year, we invite a gong therapist who conducts an hour-long meditation exercise with the help of sound bowls and gongs.

Members will receive an e-mail reminder of the upcoming topic so that they can prepare their questions. The two leaders of the Pink Bolero Association provide the attendants with fruit, vegetables and mineral water, thus increasing the feeling of “you are important here”. The members speak shortly during the first half-hour, a period when new attendants can introduce themselves. This will start a joint communication that establishes mutual trust and increases group co-ordination. The topical program follows during the next part of the afternoon, which ends with 10-15 minutes of movement therapy as a chill-out session. At the end of the meetings, in one final round, we give everyone the opportunity to express their feelings and thoughts about the program of the day and to make suggestions for upcoming occasions.

3.2. PERSONAL EXPERIENCES OF GROUP MEMBERS

Such a paper about the functioning of the breast cancer self-help group would not be complete without presenting the personal experiences of members. We asked the group members – regardless of how long it took to get their first diagnosis and at what stage of the disease they were at – to describe their experiences and impressions in the self-help group and to try to compare them with the support provided by relatives, family and friends. 24 members of the Pink Bolero group¹ undertook to summarize in a few sentences their experiences, changes and achievements that the meetings gave them. Due to the spatial limitations of this paper, it is not possible to publish all the opinions here, but we would like to show some of the most important ideas they describe below, while also trying to introduce the members and their life situations:

3.2.1.

A was diagnosed with breast cancer at the age of 45. She was shocked by the illness and therapeutic options, and as medical events accelerated, so were her husband and her two school-age children. She came to the group following the invitation of a fellow patient. The female patient, who was initially extremely inhibited and anxious, has been a member of the Pink Bolero Association for the third year without interruption. These days, she is the one who “encourages” newcomers. She is currently symptom-free and goes to her doctor every four months for a check-up in order to receive tight monitoring.

“... When I found out I was sick, I was lost, I felt like I had fallen into a very deep hole. There was no one around me who could understand what was going on in my head. My family loved me and flooded me with their love, but they couldn't help me. They didn't have a single sentence for me which I would have believed, I was sick of them trying to make it look like everything was okay, I hated to see them crying. We just couldn't do anything with each other. They made me feel beloved, but I still felt like I was trying to cry for help from a deep hole, help me out, pull me out, I want all this finished, I want to be normal like you, but they just looked down at me from the edge of the hole and just told me to calm down, everything's going to be okay! ... And they didn't understand me. I cried, sometimes I yelled, sometimes I was just quiet, constantly or in waves. And then one day, a friend of mine asked me if I wanted to meet people who had similar problems to mine... She took me to the Association, and I met friends who understood me, who I could believe telling me that I would be cured. Who could answer my questions, my fears, and who immediately and unconditionally accepted me among themselves and surrounded me with their love. I got a lot of spiritual support from Pink Bolero, and I learned to meditate... I became a part of very good conversations, received pieces of useful advice. I'm very grateful to be able to belong here.”

¹ Publishing the members' answers is anonymous, and has been authorized by each group member in a written form.

3.2.2.

B received the diagnosis of a malignant breast tumor at the age of 43. Like *A*, she also had a supportive family background when she arrived at the group. She tried to keep her illness a secret among her colleagues and acquaintances. She sought to address her fears and insecurities by visiting the Self-Help Association.

“... It all started with detecting a bump in my breast and immediately feeling that this wasn't going to be simple... A few days later, I was at the next Pink Bolero gathering. It gave me great strength to have a conversation there without taboos, with people who had proceeded along the path that stood before me just a few weeks, a few months earlier and even with those who had gone all the way several years earlier. They gave me real strength through meeting them, I could see there's life after chemo and surgeries. I received advice, practice, lots of useful information to prepare for chemotherapy, to process hair loss and wig wear. I have been helped to transform the terrifying events that have happened to me for my own benefit, which still determines my self-esteem, my faith in myself, my spiritual strength.”

3.2.3.

C was 65 when she joined the Pink Bolero Self-Help Association. Her retirement was about to begin when her mammogram revealed her illness. Her husband, though very supportive from the start, was somehow concerned in an embarrassing way – as she put it. She often felt that her adult daughter, who was mostly trying to gain knowledge from the internet, was almost lecturing her how to go about this disease. She is still undergoing treatment, and still needs radiotherapy after completing chemo, but today she is much more confident and has learned to say “no” to unsolicited suggestions.

“...I summed up in a few sentences what the group provided me and what my family could not give. Listening to these stories will make our own situation more acceptable... we share life coaching advice that we've tried before, making it easier to follow new ideas... Accepting and enduring our destiny requires a lot of patience and perseverance, and the strength of the group is a help in this. ... We cannot speak so openly to the family about anything that happens to us, there are many barriers so that they do not get scared; so as not to worry them; do not sadden them; they don't really know what we're going through; their advice comes from laypeople, they are just guessing. In the group we receive credible information.”

3.2.4.

D was diagnosed with breast tumor with bone metastasis at the age of 48. She arrived in the group 18 months ago with a strong fear of death and anxiety. She found it difficult to understand the words of the doctors, the only thing she heard was that her illness would soon enter the final stage. For a long time, she researched treatment alternatives available on the internet, she felt that no one could help her. She could not

even deal with the support of her loved ones, and heated arguments became frequent at home. Her bone metastasis is still being treated, but it's completely symptom-free. Breast correction may soon take place, which she is particularly pleased about, as she can regain her lost confidence.

"When you feel like everything is lost because you find out you have breast cancer... there is a group in which there are asymptomatic women or even those in treatment who help each other, with the help of their experience they show that there is a way out, you should not give up the fight... It's a tremendous force, it's a great help to talk about everything. The shared experiences created a community of a lifetime, friendships were formed through the programs together. ... The family helps, loves me, while they are deeply worried... the group provides experience, professional help, and also nurtures the soul. ... It's nice to talk about what's in your brain all the time. This can only be solved in this type of group."

3.2.5.

E was diagnosed with breast cancer at the age of 51 and the disease had already metastasized to her liver. According to her own story, she "let herself go a little bit" after the birth of her two sons. For her, the news of the diagnosis mean that she was facing the end of her life, that is, death. There was doubt about the metastasis tumor removal, and the extra weight caused her heart to be more burdened by chemotherapy. When she joined the group, her self-esteem was low, she lost confidence in herself, she was characterized by self-deprivation. The metastases are gone from her liver, and breast surgery is coming soon.

"What did the Pink Bolero group give me? It showed that you can survive a cancer diagnosis for many years, with a good quality of life. It taught me to rejoice in what I have, to appreciate the beauties and pleasures of life. To take care of my health because there's only one. It started me on a road that led me to lose (so far) 14 kilos, I work out almost every day and enjoy it!"

3.2.6.

F became ill at a very young age, received a diagnosis of breast cancer at the age of 28. She was devastated by the loss of her thick, long hair and the physical and psychological symptoms caused by early menopause. However, participation in the group has very much changed her attitude to the disease. In addition to the treatments, she started working again, continued her studies and became so comfortable with wearing a wig that a photo album of her will be released soon.

"It's a great help to see that your fellow group member is over with what's in front of me... with a lot of advice, you can prepare the others, they tell you what to expect, as it is possible to make the side effects of treatments easier and more bearable... and it is good to see that anyone who has already gone through the treatments is well and living her daily life in the same way she did before."

Based on the above ideas, we can see how self-help group helps the women concerned, and this is noticeably in line with what is described in the literature (i.e. Docherty, 2004; Yaskowich & Stam, 2003). They contain all the specific forms of help that a self-help group can provide in addition to family support. It is extremely important to see that people who share their problem are better able to understand each other, since they know the feelings (pains, fears, etc.) that they talk about it and ask each other questions. Understanding each other, talking in “one language” can help them heal and better understand the thoughts of outsiders and family members about their illness. All of this can help those affected to improve relationships and communication with family and other relatives and friends.

In addition to group support, one of the most important things such a patient community can give is motivation. The realization of what the others could achieve may be achieved by anyone here eventually makes them try. In many cases, we see that those who do better in an exercise try to help and encourage the weaker ones, and that is what gives all of them tremendous strength. Helping each other is an uplifting feeling for both parties – both those who give help and those who receive help – and words of encouragement increase self-esteem.

Those affected are consistently positive about being in a company where there are no taboos, where everyone knows exactly what kind of disease they are coping with. From the examples above, it can be seen that people of all ages experience belonging to the group in a similar way. Perhaps the greatest achievement for a health psychologist is when she can experience that tension and anxiety are dissolved, that hopelessness is replaced by healing; but most of all, the patient's belief in herself that she is able to competently fight the disease. It is very important that during the course of education the patient understands the mechanism of her disease and therapies, by which the adherence increases, the doctor-patient communication develops. As a group leader, it's great recognition that group members love going to Pink Bolero, that they take pride in being a “Pinky girl” („Pinkes lány”), and they can't wait to get back together between meetings. This is the result of finding understanding and attention in the group that they need. It is also an important result of our Association that several people keep in touch outside the sessions, help, support each other, and friendships have developed. Members who have experienced the disease and therapies almost take the newly diagnosed under their “wing” and encourage them to come to the self-help group in view of treatments, to change their relationship to the disease, to strengthen them in body and mind.

A family member (husband) called me once after his partner, who had been previously diagnosed and deemed completely hopeless, returned home from a group meeting: “... *you are doing an incredible job.... never give it up! Thank you so much for getting my wife back.*”

3.3. CHALLENGES IN THE LIFE OF GROUPS – DIFFICULTIES IN GROUP MANAGEMENT

The psychologist leading the group feels that her work is effective when the dissolution of anxiety is felt, or when she gets positive feedback. However, more difficult situations may also occur. For example, the presence of someone in the group whose behavior may disturb others may create tension in members. It is important to keep the frames tight and avoid unpleasant situations. Several studies in the literature draw attention to the problems related to the group structure that can disrupt group dynamics and diminish volunteering to join in (e.g. Docherty, 2004; Galinsky & Schopler 1994).

Losing a group member is perhaps the biggest challenge for a team leader. The death of a member, a close acquaintance, brings about painful, difficult emotions in everyone. Death due to a disease of the same type may even become a taboo among group members, as they may have questions that are not based in reality, which may cast doubt on the effectiveness of hard-to-bear therapies and develop a negative view of the future. Tension and anxiety can increase at a time of losing a member. The team leader asks questions about how members will accept the loss of a group member, how it will affect them, how much it will throw them back in terms of treatments or healing, and how this can be resolved in the right way. However, it is important to bear in mind that the emotions of grief should not be suppressed, since unprocessed loss can be a heavy burden for the individual in the future. The Pink Bolero Association, relying on the available literature, developed a common commemoration protocol (e.g. Hajduska, 2010; Zana & Hegedűs, 2009). This stipulates that at a group meeting following such a painful loss, each member can commemorate the deceased in a few sentences, totaling about thirty minutes, and then commemorate the diseased in silence for a minute. It is important for those present to feel that they are not alone in their grief, that they can count on each other, that they can count on each other's support.

4. DISCUSSION

Self-help groups are of paramount importance to patients and their relatives, but their activities are also essential at the societal level, as they support the work of health care institutions and in many cases reduce their burdens.

Group members who responded highlighted “better orientation and professional information” as the practical benefits of patient groups. In this way, they were able to accept their disease, understand the importance of different therapies, and manage side effects. These results are described in several studies and are also mentioned as an advantage for support groups operating in the online space (e.g. van Uden-Kraan, 2008). It was clear from the participants' narratives that loneliness, feeling alone as a psychosocial stressor are often confronted after diagnosis. The results show that even participation in online support groups can help to prevent the effects of this stressor.

The studies also showed that members of self-help groups communicated more easily with medical staff as a result of the sessions, asked their doctors more confidently, and were free to talk to relatives about their condition. A Pink Bolero group member described the development of her communication as follows:

"... I was afraid to ask certain questions from a doctor or a surgeon... I thought I'd had no idea about it anyway, they'd think my questions are stupid, or they'd just turn me down, and besides my troubles, I'd even have to be ashamed... but through the group I learned that I have the right to ask questions, and I need to know what happens to me, what happens to my body. And it was something else, I learned during my studies how important it is. And then I started asking a surgeon about my things, and it was good for me, because I came to understand a lot of things..."

Patients experienced a great improvement in their well-being and in their social relationships as a result of group activities, which reduced their loneliness. Supportive self-help groups were considered by those involved to have provided them with a sense of belonging to a special community and unconditional acceptance. Togetherness helped and facilitated relationships with family and other relatives, friends; their self-esteem and sense of control, their self-efficacy increased, and they felt that they, too, were able to do something for themselves.

Lessons learnt from the self-help groups

In my clinical work, I often help oncology patients by individual support and personalized interventions along their journeys through the disease. Since we founded the Pink Bolero Self-Help Association, I have found that in people who participate in group receptions, tension and anxiety are relieved faster than those attending individual therapies. Since these oncology patients are not anxious at a pathological level or show symptoms of depression, they get rid of those symptoms more quickly when they receive understanding support in a self-help group, whose members have similar problems. The development of group cohesion is important for patients, it gives strength in coping with the disease. Group sessions bring the members together. The role of the health psychologist is extremely important in the cohesion of the group and in the coordination of tasks. The activities of the self-help group, the assistance of patients in this form, and the conversations with the members have also proven to be effective. Patient groups in hospitals and other institutions help patients to process difficult times for them. Connecting to a self-help group is now available to everyone, but this option is still unknown to many in need. I consider it an important task to present the importance of groups in several forums, in institutional newspapers, in the media, even in health programmes, and to explain their activities. In addition, I believe that there is a great need for more groups representing other specific areas, so that this form of support, self-help, can reach everyone.

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