
The Changing Role of Organized Patient Support for the Chronic Pelvic Pain Patient

2

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Introduction

While mutual aid groups and friendly societies were already a popular phenomenon in the nineteenth century at the time of the Industrial Revolution, with the rise in Socialism and Trade Unions [1, 2], modern patient support groups evolved from the mid-twentieth century's member-focused self-help and support group concepts into support and advocacy groups with an increasing range of tasks to meet the demands of today's electronic world and a need for high-quality, reliable information, in addition to providing emotional support and practical information for patients. In recent years, the emergence of the concept of patient empowerment has led to an increasing need for patient advocates to represent their fellow sufferers in the complex and political world of health with the aim of achieving patient-centred healthcare and ensuring that the patient/consumer has a voice in all decision-making about his/her healthcare at all levels. This includes, for example, such diverse issues as education and awareness campaigns for the general public as well as the patient, lobbying authorities in relation to health policy, patient safety, access to social benefits, reimbursement of treatment, patient participation in clinical guidelines and standardization, involvement in research, fund-raising and much more besides.

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Decline in Community 'Umbrella' Led to Rise in Support Groups

Our increasingly mobile society has led to a decline in the close-knit family network with family members now scattered not only all over the country but often throughout the world, while many people no longer know their constantly changing neighbours. In developed countries in particular, this has resulted in a loss of care from the extended family or community 'umbrella' that existed in the past. Furthermore, the family doctor who once knew the entire family has often been replaced by primary care clinics where patients cannot always be sure of seeing the same provider twice. Home visits by the family doctor which formerly played an important role in primary healthcare are now greatly reduced, often applying to emergencies only, while the district nurse has disappeared from the scene in many developed countries. When combined with economic cutbacks in home care services, this means that chronically ill people may often be isolated and left to fend for themselves.

Patient Support Groups in Urological and Gynaecological Chronic Pelvic Pain Syndromes

Patient support groups in the field of urological and gynaecological chronic pelvic pain syndromes really began to emerge with the foundation of the Interstitial Cystitis Association (ICA) in the USA in 1984. By 1993, IC groups were forming in Germany, the UK and the Netherlands and soon began to fan out around the world. In 1994, the National Vulvodynia Association (NVA) was formed in the USA by five vulvodynia patients, followed by the Vulval Pain Society in the UK in 1996. The American Prostatitis Foundation was set up in 1995 and likewise stimulated support groups in this field for men in other parts of the world, notably in the UK.

It was not easy. They were faced with a deep-rooted social taboo or stigma on any discussion of embarrassing disorders between the waist and the knees. While bladders and urine were topics to be avoided in polite society, the very intimate problems of vulvodynia—let alone sexual pain—were completely off limits and only raised in hushed, embarrassed tones in the doctor's office by the bravest of patients. Nevertheless, support groups got off the ground simply because a few very courageous patients were willing to stand on platforms and tell the world that they had a bladder or vulvovaginal pain disorder in order to raise awareness so as to help ensure that other patients would receive the right diagnosis and treatment at the earliest possible stage.

This social taboo still exists today, although in some cultures it is more intense than others. It also creates a problem for support groups with regard to sponsoring since the taboo aspect limits the field of potential sponsors. National enterprises that may be very willing to support, for example, cancer, heart, diabetes and kidney patient associations, are extremely reluctant to have the name of their company linked to embarrassing urological or gynaecological disorders. It is interesting that while prostate cancer has in recent years become an 'acceptable' topic of conversation, interstitial

cystitis (IC)/bladder pain syndrome (BPS) or vulval pain disorders still have not, and patients continue to feel stigmatized and isolated. However, the support groups give them an opportunity to discuss their disorder openly with other patients, and this may in turn also help the patient to be more frank with their doctors about issues they find too embarrassing to discuss.

Support Group Focus: Single Disorders or Combinations?

Although patient support groups traditionally focus on one specific disorder, we have seen the emergence here and there of umbrella organizations covering several chronic pelvic pain syndromes in one association. In practice, however, it is quite difficult to combine groups of disorders where the patients may have completely different symptom priorities while at the same time paying adequate attention to each priority and very importantly ensuring that the support group has sufficient expertise on each disorder. Whereas the trend in recent years has been to look at what the different chronic pelvic pain syndromes have in common, these may not necessarily be the aspects about which patients are specifically concerned. On the other hand, it may be difficult to obtain research or other grants for specific urological and gynaecological chronic pain syndromes, but potentially easier if presented in a wider context of chronic pelvic pain syndromes. Alliances between support groups in this field may therefore be useful.

Awareness, Information, Education

It goes without saying that the less well-known a condition, the more time has to be devoted to raising awareness and providing information since the patient organization may be a main source of practical information about that condition. While a primary objective is to ensure that more patients with symptoms consult a doctor, this is not going to be effective if healthcare professionals have never heard of the condition. This particularly applied to interstitial cystitis/bladder pain syndrome in the early days of the first IC patient support groups. Not only was it virtually unknown among the general public but also little known among healthcare professionals. This even applied to urologists who saw few if any IC/BPS patients since primary care providers were simply not referring patients to them. Consequently, the support groups' campaign to raise awareness at a professional level was initially aimed at both primary care and specialists, but has gradually been expanded to include the allied professions, with urology nurses and pelvic floor physiotherapists later taking a keen interest in chronic pelvic pain syndromes. With an increase in knowledge of comorbidities, attention also had to be paid to raising awareness among gastroenterologists, rheumatologists, neurologists and of course pain consultants and encouraging them to cooperate in multidisciplinary care. This was and still is a challenging task.

Collaborative Action to Raise Awareness

Approached by the ICA, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in the USA played a valuable role in education and science by holding scientific symposiums for interstitial cystitis, attended by patients and professionals from around the world, while the German ICA organized symposiums which formed an important step in raising awareness in Europe and educating both doctors and patients. The Society of Interstitial Cystitis of Japan (SICJ) and a Japanese patient support group were set up in Japan in 2001 and organized a successful series of the International Consultation on Interstitial Cystitis Japan (ICICJ) in Kyoto, involving patients in these scientific meetings. In the meantime, support groups were on the rise around the globe, giving patients the chance to meet each other, share experiences and organize patient gatherings with expert speakers. This was combined with publication of leaflets and brochures, fact sheets on every imaginable topic and treatment, books, videos and ultimately websites in a variety of languages including English, French, German, Spanish, Portuguese, Japanese, Chinese and Russian, to name but a few (see Table 2.1). These activities were assisted by medical advisory boards that played an essential role in helping to ensure that the medical information was absolutely accurate.

Today, much of the information for patients is available for downloading on the patient support group websites, providing reliable information for patients on symptoms, diagnostic procedures, all available treatment modalities and other issues which have an impact on the life of the patient, while both patients and clinicians are kept updated on developments by regular newsletters (see Table 2.2). Webinars are a recent innovation for both patients and clinicians, while Facebook, Twitter,

Table 2.1 Examples of information available from patient support groups

Types of information	Topics covered include
• Brochures, leaflets, fact sheets • Books • Newsletters • Educational videos/DVDs for patients and clinicians • Webinars • Website • Research updates	• Symptoms • Diagnosis • Pelvic and urinary tract anatomy • Individual drugs and therapies • Complementary and alternative medicine and therapies • Natural products • Pain management/toolkit • Comorbidities • Diet • Sexual intimacy • Pregnancy • Self-care/coping/lifestyle changes • Survival strategies • Fitness • Employment and disability • Specific information concerning men, women and children • Information on healthcare providers for patients

Table 2.2 Facilities and services offered by patient support groups include the following (varies greatly depending on the size and resources of the support group)

• Can't wait toilet/restroom cards
• Facebook/Twitter/YouTube/blogs
• Face-to-face meetings/conferences
• Virtual meetings
• Helplines (telephone and e-mail)
• Online forums
• Online shops
• Online surveys/questionnaires
• Product information
• Toilet/restroom maps per region
• Toolkits for local groups
• Workshops

blogs and YouTube offer new opportunities and challenges. A big change since the Internet revolution is that the information offered by the support groups is no longer restricted to members in a single country, but used by patients, their families and healthcare providers around the world.

This has led to the emergence of the ‘expert patient representative’ who today reads not only patient information but also scientific literature and attends relevant medical conferences in order to keep the support group members updated on the latest developments and thereby give them hope. A drawback is often a lack of (affordable) access to the scientific literature. Some publishers are offering special patient rates for purchase of articles or open access, but mostly this is not yet the case. Conference registration fees for patient representatives from the support groups can be another financial obstacle.

Increased education and information at both clinician and patient levels have led to the diagnosis and treatment of far more patients worldwide, while the patients themselves have a better understanding of the disease and the different types of treatment. Patient support groups specifically do not encourage patients to self-diagnose, but make sure that patients are well informed so as to allow them to participate fully with their healthcare providers in the process of diagnosis and management. Where necessary, the support groups also provide the patients with information concerning providers with expertise in the field: urologists, urogynaecologists, urology nurses, dieticians, pelvic floor physiotherapists and counsellors, as well as practitioners of alternative forms of treatment.

Emergence of the Internet Presents a New Challenge

The emergence of the Internet, e-health and support group websites with their detailed information is rapidly leading to a changing doctor-patient relationship which, particularly in the case of lesser known conditions, may result in the patient having more up-to-date knowledge than the doctor. Patients not only use the Internet to seek information but also to double-check what the doctor has said and prescribed; patients have

become consumers who now question their doctor's decision, which they never did in the past. This is going to require a new approach by healthcare professionals who will need specific training in medical school to deal with this modern phenomenon so as to be able to communicate and interact with patients arriving at their appointment armed with computer printouts.

Information for Low-Literacy Populations and Non-native Speakers

In this electronic age, it is easy to think of information either on the Internet or in leaflet form as being accessible to all. But of course this is not the case. There are still large parts of the world with a low-literacy or illiterate population where leaflets, brochures and Internet information for patients are going to serve little purpose. Healthcare workers and patient organizations in these parts of the world have been successful in spreading information in the form of cartoons and videos and using music, dance and drama for local rural audiences so as to convey the message in a simple but effective way. With increasing low-literacy migrant populations in the Western world and population groups who do not speak the language of the host country, it may be necessary to make greater use of these methods, including videos with voice-overs in a number of different languages, to make sure that understandable information reaches everyone.

Practical Support

All the forms of support provided by patient groups help to ensure that patients are aware of available treatment, understand why it has been prescribed, share decision-making, learn how to cope, adapt their diet and lifestyle where necessary and play an active role in self-care, thereby improving their quality of life and helping to rehabilitate themselves into society.

Emotional Support and Empathy

An important aspect of the work of support groups has always been to provide personal emotional support through patient-to-patient (peer-to-peer) telephone helplines in the knowledge that a trouble shared is a trouble halved. These helplines provide a listening ear, while patients calling know that the listener is also a patient and therefore has personal experience of the problems and will truly understand. These telephone helplines have in recent years been augmented by email helplines. Sharing a problem helps the patient to overcome the sense of helplessness and hopelessness, combat anxiety and panic, come out of their isolation, accept the new situation and take the first steps towards developing coping strategies, looking at what they can do rather than at what they cannot do. In this way, patients can start to improve their

quality of life. It should be emphasized, however, that suicidal patients need professional counselling and that this task should not be left to patient support groups, as has too often been the case in the past. Some of the larger support groups nowadays have professional counsellors to help man these helplines.

Patient meetings, large or small, give members and their families the opportunity to talk to other people in the same situation and be reassured that they are not alone with this condition. Those who are unable to attend face-to-face meetings benefit from today's online forums that allow members of support groups to exchange experiences, ask questions and discuss day-to-day problems. Support groups encourage patients to openly discuss intimate issues such as sexuality and provide information about professional counselling for their sexual problems. This social interaction with their fellow sufferers helps patients overcome the sense of hopelessness and helplessness that often results from chronic pain and instead regain a feeling of self-confidence and the ability to gradually assume a degree of responsibility for the management of their chronic disorder.

An additional advantage of support group helplines and meetings is that they generate a wealth of feedback, giving patient support groups a comprehensive picture of the whole spectrum of the condition, since patients will tell other patients things they would never tell their doctor. Furthermore, support groups may have personal contact with hundreds and often thousands of patients, making the groups a huge potential source of information for research projects.

Volunteer Participation and Continuity

Many patients have found that the opportunity to participate in the many aspects of running a voluntary support group has given their life new meaning with a positive rather than negative outlook, thereby also helping to improve their own quality of life. Rather than simply passively receiving help, they learn to give help to others too. It is also vital for support groups to involve as many patients as possible, even in the smallest tasks, to ensure that there are people available to take over when chairs and board members retire, and thereby guarantee continuity of the support group. This is one of the biggest challenges faced by support groups. A common problem encountered is that they are often started by one or two patients and everyone expects them to continue forever. When a chair steps down, it is often difficult to find others to take over. While the very large associations often survive better because they may have sufficient resources to be able to take on a paid CEO and/or paid secretary, any sudden cut in funding may have dramatic consequences.

Empowerment

'Empowerment' of patients has been a buzzword in recent years, but not everyone knows exactly what is meant by the term. In its simplest form, it means that patients are no longer bystanders in their own care, but now have the opportunity to play an active

role in their treatment and care. According to the European Network on Patients Empowerment (ENOPE), empowerment is about designing and delivering health and social care services so as to enable patients to take control of their healthcare needs [3]. An empowered patient is an informed patient who understands his/her health condition, is able to make informed choices, can interact with healthcare providers and is capable of making the necessary lifestyle changes. Patient support groups provide their members with the tools to do this. However, this in itself is not sufficient to create patient empowerment: for it to succeed, there needs to be a patient-centred culture in the healthcare system, with an interactive partnership between patients and their clinicians and other stakeholders [4].

Patient Advocacy

With the rise of the expert patient advocate, patient support groups are better able to engage with all stakeholders, including healthcare providers, health insurers, healthcare regulators and industry. While the patients are beginning to gain a voice in decision-making, there is still a long way to go to ensure optimum care and access not only to treatment but also to reimbursement of that treatment and eligibility for a wide range of social and disability benefits.

At present, patient support groups and their representatives are regrettably often involved in decision-making only at the end of the process, as a kind of token window-dressing, when all important decisions have already been taken by the professionals. For patient participation to have any value, patient representatives need to be involved in the entire process.

An additional problem faced by patient organizations is that while many meetings for stakeholders including patients are organized by national and international authorities, with many promises made and declarations signed, there is often little evidence of concrete action by these authorities. Nevertheless, despite these problems, there have been many positive achievements. If the support groups continue with their progress, like the hare and the tortoise, they will find that ‘slow and steady’ eventually wins the race! A strong participating voice for the patient will ultimately lead to more and better patient-centred healthcare.

Participation in Research

Right from the start, patient support groups have actively stimulated research; today, they are also increasingly participating in research projects. Support groups and their members can help to identify and draw attention to areas hitherto neglected by researchers but which patients feel to be of great importance and which directly affect them. In this way, they can help find better treatment and even ultimately a cure for the disease. One practical way in which support groups and all their members play an active role in research is through surveys, both nationally and internationally. This can be of great value to research projects and has become much easier with the emergence of the Internet and online surveys.

Patient Safety

Patient support groups and their umbrella organizations are very involved in all aspects of patient safety including in all areas of healthcare, clinical trials and research projects. The International Alliance of Patients' Organizations (IAPO) has created a useful toolkit to help patients and their organizations engage with stakeholders and have a voice in actions that reduce harm to patients and improve the quality and safety of their healthcare system. This toolkit also provides advice and tips on how to advocate and build partnerships to achieve patient safety goals and on communicating messages to patients and other healthcare stakeholders [5].

Involvement in Clinical Guidelines and Standardization

As already mentioned, patient support groups are a mine of information on the entire spectrum of a syndrome or disease and can therefore make a valuable contribution to clinical guidelines, taxonomies and standardization of terminology and definitions. While healthcare professionals may have a more limited view of just a few links in the chain, support groups have a more comprehensive view all the way along that chain and are likely to be more aware of the impact of additions or changes in terminology and definitions on the patient in practical terms. This means that more patient representatives need training in these fields, including on coding issues, in order to be able to participate fully in this kind of work and not just serve as a rubber stamp at the end of the process. It is particularly important in relation to the International Classification of Diseases (ICD) which may impact their diagnosis, treatment and eligibility for reimbursement of that treatment and the full range of social benefits. The International Continence Society (ICS) has led the way in fully involving patients in standardization processes; more professional societies need to follow this example [6].

Conclusion

While the basic task of a support group has always been one of raising awareness, providing information, offering emotional and practical support to patients and their families and giving patients the opportunity to have contact with each other, the rise of the Internet has greatly increased the possibilities and outreach. Advocacy on behalf of patients at local, national and international levels is now more important than ever in order to achieve patient empowerment and patient-centred healthcare, with patients participating in decision-making as partners. Support groups in the field of chronic pelvic pain syndromes have had to overcome the additional burden of stigmas and taboos; this has made awareness campaigns and fund-raising even more of a challenge for these organizations.

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