

Patient advocacy and arthritis: moving forward

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Abstract Patient advocacy is based on the premise that people have the right to make their own choices about their health care. Personal advocacy is centred on the experiential expertise of the individual affected by the condition, whereas group advocacy is grounded on patient-centred strategies and actions. The first patient advocacy groups for arthritis were set up over 20 years ago in the USA and have subsequently spread to many other countries. This paper discusses the growth and impact of personal advocacy as well as recent developments in group advocacy in the Asia-Pacific region, Europe, and North America, in terms of arthritis awareness, research, corporate partnerships, and the Bone and Joint Decade global initiative.

Keywords Arthritis/prevention and control/therapy; Patient advocacy; Patient rights; Patient participation; Self care; Self-help groups; Physician-patient relations; Intersectoral cooperation (*source MeSH, NLM*).

Mots clés Arthrite/prévention et contrôle/thérapeutique; Défense malade; Droits du patient; Participation malade; Auto-traitement; Groupe soutien social; Relation médecin-malade; Coopération intersectorielle (*source: MeSH, INSERM*).

Palabras clave Artritis/prevenición y control/terapia; Defensa del paciente; Derechos del paciente; Participación del paciente; Autocuidado; Grupos de autoayuda; Relaciones médico-paciente; Cooperación intersectorial (*fuentes: DeCS, BIREME*).

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Voir page 119 le résumé en français. En la página 119 figura un resumen en español.

Introduction

Patient advocacy, which goes hand-in-hand with patient empowerment and patient education, is a fundamental concept within the current movement of health care reform (1). Over the past 20 years, people affected by arthritis have turned to patient advocacy as a means to create awareness and to call for and enact change at the personal, community, government and/or society level in order to improve quality of life. Patient advocacy embraces the concept that people have the right to make their own choices about their health care. It assumes that to be healthy, people must be able to bring about change in their personal behaviours and in the social situations and institutions that influence their lives. In the context of arthritis, personal advocacy is centred on the experiential expertise of the individual affected by the condition, whereas group advocacy is grounded on patient-centred strategies and actions. This paper will discuss the growth of personal advocacy and its impact on patients with arthritis, as well as recent developments in group advocacy and their potential impact on society's treatment of the condition.

Personal advocacy and empowerment

Gadow defined personal advocacy as “participation in valuing the unique meaning which the experience of health, illness or

suffering is to have for that individual” (2). It implies that persons should be assisted to exercise authentically their freedom of self-determination, “authentically” meaning a “way of reaching decisions which are truly one's own — decisions that express all that one believes is important about oneself and the world, the entire complexity of one's values” (2). Empowering a patient's experience and perspective are at the heart of personal advocacy.

Empowerment has been broadly defined as an enabling process through which individuals or groups take control over their lives and environment (3). The word “empowerment” builds upon the Latin root *potere*, from which the words “power” and “freedom” are derived. Empowerment is a concept that emanated from philosopher Paulo Freire (3), who developed a methodology using critical consciousness of literacy to people in Brazil. The Freirian method stresses equality and mutual respect between group members and facilitators who engage the group in problem-solving dialogue.

The empowerment philosophy of patient care is based on several tenets. First, it assumes that patients are responsible for making important and often complex decisions about their medical care. Second, it assumes that because it is patients themselves who experience the consequences of both having and treating their medical condition, they have the right to be the primary decision-makers in this regard. Therefore, according to

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this philosophy, the primary function of the health professional is to prepare patients to make informed decisions about their own medical care (4).

Advocacy at the individual level challenges the traditional biomedical model of arthritis care. Box 1 compares the traditional biomedical model of care with a personal advocacy and empowerment model. In the personal advocacy and empowerment model, arthritis patients are seen as experts on their lives and experience with the condition, while health professionals are seen as experts on the medical aspects of arthritis and serve as an information resource.

Personal advocacy therefore enables patients with arthritis to make informed decisions about their disease and to be responsible members of the health care team. To do this, patients must be informed about their condition and their treatment options, and given the opportunity to express their understanding, values and beliefs. They must be given the time and encouragement to ask questions, raise concerns, and express their feelings about what is happening to them.

A critical component of effective personal advocacy is communication between the patient and the health professional. The patient's task is to express all of his/her concerns, including those of a psychosocial nature, while the health professional's task is to address the patient's concerns. Both health professional and patient:

- Share models of disease and systems
- Share goals for treatment
- Agree on treatment goals and set priorities
- Share models of treatment
- Identify potential difficulties in adherence to treatment
- Plan how to overcome these difficulties (5)

Patients who participate in the making of decisions about their care are more satisfied overall, more likely to adhere to treatment,

and more likely to adapt to living with arthritis (6). Patient–health professional relationships which are grounded in effective communication, trust, reciprocal information, mutual understanding and respect are a foundation, and even a prerequisite for effective and efficient care.

Health information and patient education

The explosive growth of the Internet has increased consumer demand for health information and fuelled the expansion of personal advocacy and disease self-management. The Internet has become a significant tool used by advocates to inform, mobilize grass-roots attention and to effect change. However, distinguishing reliable information has become a challenge for the consumer, prompting academic institutions to offer consumer guidelines for surfing the Internet. In some countries, direct consumer marketing by industry has resulted in higher patient demand for immediate information on medications and treatments (7).

Patient education is a continuous process, integral to optimal health care. Such education includes organized awareness and information about self-care, psychosocial support, and behaviour related to health and illness. It is designed to help patients, their families and caregivers to understand the disease and the treatments proposed, and to cooperate with health-care providers (8, 9). Some patient education programmes have a beneficial impact on selected variables of disease status, patients' well-being, outcomes and cost of treatment (10–14), while others do not (15, 16). Benefits to patients include reduced anxiety, depression and pain (17), reduced feelings of helplessness (18), and increased functional status (19). Other research confirms the beneficial effect of cognitive behavioural education on pain management (20), understanding the impact of psychological factors on coping and disease management, and quantifying their effect on health status (21).

The distinction of patient education as a “planned, organized learning experience designed to facilitate voluntary adaptation of behaviours or beliefs conducive to health” (22) plays an important role in promoting personal and group advocacy. Through well-defined goals and learning objectives, the focus of patient education is primarily on changing beliefs and behaviours related to health. Other factors, such as knowledge, communication abilities, assertiveness and sense of control, while having an impact on health outcomes, also contribute to the skill sets of the patient as advocate (see Box 2). A seamless transition is seen in the outcomes of many education programmes in North America and Europe for patients with arthritis: the educated patient evolves into an “arthritis patient advocate”, a leader of people with arthritis in their community.

Self-management programmes

Today's arthritis patient advocate is the offspring of the self-help movement of the late 1970s. A defining moment was the development in 1978 of Lorig & Fries' Arthritis Self-Management Program (ASMP) (23), which became the prototype for the Arthritis Foundation's flagship education programme, the Arthritis Self-Help Course. The ASMP incorporates participatory educational dialogue about the patient's needs and issues in managing arthritis, rather than content defined by health professionals. Patients learn specific skill sets, such as problem-solving, goal-setting and action-planning behaviours. The programme is co-led by arthritis patients and health professionals who are trained instructors.

Box 1. Comparison of models of health care: traditional biomedical versus personal advocacy and empowerment

Traditional biomedical model	Personal advocacy and empowerment model
Acute diseases	Chronic diseases
Practitioner-centred	Patient-centred
Information giving	Information exchange (a meeting of experts)
Practitioner must save the patient	Patients must save themselves
Dictate behaviour	Negotiate behaviour
Treatment compliance	Treatment adherence
Paternalism (parent-to-child)	Partnership (adult-to-adult)
Motivate the patient	Assess the patient's motivation
Persuade, manipulate	Share decision-making, mutual understanding
Resistance by patient is dangerous	Resistance is information
Respect expected	Mutual respect is assumed
The patient's health is the responsibility of the health professional and the public health system	The patient's health is the responsibility of the patient

Box 2. Personal advocacy: situation-specific skills^a

Skill sets	Description
Communication	Helps patients to express needs, ask questions, negotiate behaviours and actions, and advocate for their rights.
Information seeking	Helps motivate patients to gain relevant information about arthritis vis-à-vis their needs.
Assertiveness	Helps patients take action in situations where they perceive themselves to be timid, e.g. communicating in patient–health professional relationships or in seeking a second medical opinion.
Decision-making	Allows a patient to weigh available options and reach a decision that is compatible with his or her values, e.g., if a patient must choose between treatments that have evidence of visible side-effects, such as hair loss or weight gain, the patient may weigh these two options against the importance he or she places on his or her body image and then choose the one that is consistent with this value.
Coping	Allows a patient to manage various stressors so that excessive stress does not interfere with the capacity to evaluate a situation and make decisions compatible with his/her values. Some patients become “psychologically paralysed” when told that they have arthritis and tend to want others, usually the health professional, to make decisions for them.
Social support-seeking	Allows a patient to seek and secure the type of support he or she wants from others, whether it is instrumental, emotional or informational.

^a Adapted from ref. 41.

“Self-management” has gained popularity with the dissemination of the ASMP in many countries and areas, such as Australia, China (including Hong Kong Special Administrative Region), Mexico, New Zealand, the United Kingdom, the USA and the West Indies. The term refers to the process by which patients accept responsibility for changing their health behaviours, obtaining knowledge about their disease and its treatments, and forging meaningful relationships with their health professionals (24). A similar concept is “self-efficacy”, which refers to a person’s belief in his/her capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet situational demands (25). Lorig incorporated self-efficacy into the ASMP by emphasizing behaviour and one’s belief that behaviour can be carried out in specific situations. In a 4-year follow-up study, programme participants demonstrated improvement in health status, while health care costs were reduced by US\$ 648 per year per rheumatoid arthritis patient and by US\$ 189 per year per osteoarthritis patient (26). The Arthritis Foundation’s programme has been proven to reduce arthritis pain by 20% and physician visits by 40%, increase knowledge about arthritis, exercise, relaxation, self-confidence, and decrease depression, pain, and visits to a physician (27).

Today, patient education programmes are underutilized. Although not all arthritis patients actively seek these programmes, many individuals who might benefit do not receive substantive education upon diagnosis or during treatment. While such programmes are not yet reimbursed uniformly by medical insurance in all countries, their benefits have been confirmed. A structured education programme is an integral part of the effective management of arthritis.

Patient advocacy in medical education

The Patient Partner Program (PPP) is another example of empowerment and patient advocacy. Originally developed at the University of Texas (28, 29) and supported by Pharmacia and Pfizer, PPP provides training for medical students on appropriate methods for conducting physical examinations of joints, muscles and surrounding structures. A unique feature is that training sessions are conducted by people with rheumatoid arthritis who

have become certified “patient partners”. This approach is conceptually based on the value of the patient as a partner in medical teaching of arthritis (30). One study shows that the abilities of people with arthritis are equal to or superior to nonspecialist doctors with regard to musculoskeletal examination techniques and communication skills (31). Certification of patient partners requires them to follow an extensive curriculum of anatomy, rheumatologic indications, leadership and communication skills. In 2002, a total of 600 certified patient partners participated in the programme in 16 countries.

In some countries, variations on PPP have expanded to include realistic examples of the impact of rheumatoid arthritis on daily function. In France, for example, the PPP is conducted through the Association Française de Lutte Anti-Rhumatismale (AFLAR) with the Collège Français des Enseignants en Rhumatologie (CoFER). Patients emphasize the importance of dialogue with health professionals and discuss the impact of the disease on their psychosocial, family, community and work lives. Implemented in 1998 and now established in 11 university centres, the French PPP has shown benefits for both medical students and patient trainers (32).

Group advocacy

Patient advocacy has made significant strides thanks to arthritis groups in countries such as Australia, Canada, Germany, Ireland, the Netherlands, New Zealand, South Africa, Sweden, and the United Kingdom. These groups play a pivotal role within national and regional settings by serving as the premier advocate for patients on issues such as barrier-free accessibility, employment, service providers, health insurance, research funding, disability benefits, access to care, housing, human rights, equality and education. Arthritis groups represent consumers, families and their interests. Many groups have become sophisticated in their approach to mobilizing constituents for national, regional and global campaigns.

A notable opportunity is provided by World Arthritis Day, held annually on 12 October, when patient groups, health professional societies and industry conduct collaborative awareness, education and advocacy events. Initiated by Arthritis and Rheumatism International (ARI) (33) and fuelled by the International

League of Associations for Rheumatology (ILAR) (34) and the Bone and Joint Decade (35), World Arthritis Day is becoming a rallying point for patient advocacy. For example, China (including the Province of Taiwan), Hungary, India, Japan and Thailand have conducted events attracting and educating thousands of participants.

US National Arthritis Action Plan

The National Arthritis Action Plan: A Public Health Strategy is the result of proactive actions by the US Arthritis Foundation, the Association of State and Territorial Health Officials, and the Centers for Disease Control and Prevention (CDC) to address the public health burden of arthritis, which affects over 70 million people in the USA. The plan incorporates primary, secondary and tertiary prevention strategies in a coordinated approach to reach people at the community level. Nationwide grass-roots support for advocacy prompted first-time Congressional funding of US\$ 10 million to CDC to monitor the burden of arthritis, establish state programmes for the prevention of arthritis, develop epidemiological data systems, develop national health communication campaigns, and initiate change in health systems (36)

The European "patient-citizen"

The concept of "patient-citizen" is being promoted in Europe. In 2000, the Council of Europe requested that governments associate more closely with patients on decisions regarding health policies. An example of this is provided by the adoption of the French Parliament of a "Patients Rights and Quality of the Health Care System" law in 2002 (37). Under this law, patients are responsible for decisions regarding their health status (having been provided with extensive medical information leading to informed and free consent) and thus become partners with health professionals. The law also recommends that representatives of patient groups be included on advisory boards whose decisions affect patients.

EULAR social leagues and ILAR

The European League Against Rheumatism (EULAR) (38), which has 41 member countries, is dedicated to the promotion, stimulation and support of research, prevention, treatment and rehabilitation of patients with rheumatic diseases. National patient groups called "social leagues" hold equal membership with scientific societies within EULAR. The Standing Committee for Social Leagues implements an education and advocacy programme at the annual congress, and promotes patient group activities through awards and grants for research and education projects. Since 1998, social leagues have implemented a World-wide Conference of Arthritis and Rheumatism Patient Societies to improve the effectiveness of patient groups. Other regional leagues of the International League of Associations for Rheumatology are also addressing the needs of patient groups in their scientific meetings and through their organizational structures. The partnership of patient groups and health professional societies working together has proven fruitful for increasing awareness about advocacy issues.

PARE Manifesto

The PARE Manifesto (39) is a "call to action" by a coordinating group called People with Arthritis/Rheumatism in Europe (PARE) on behalf of an estimated 103 million Europeans affected by arthritis or rheumatism. Created by the EULAR social leagues, the International Organisation for Youth with Rheumatism (IOYR) and ARI, the Manifesto was developed in 2000 to unify

Europeans in collaborating on the often ignored needs of people with arthritis. Individuals and organizations are asked to support 10 major areas of concern and interest, including the following: raising the awareness of policy-makers; delivery of health, education, employment and social services; social inclusion; legal support; development of best practices; and identifying the true costs of arthritis. Patient representatives from 31 European groups serve as coordinators within their countries. A global version of the Manifesto is currently being developed by ARI. The Manifesto offers an opportunity for patient groups to unite on a common set of goals and strategic actions.

Patient advocacy and arthritis research

Trail-blazing efforts that mobilize constituents to advocate for increased government research funding have been successful for HIV/AIDS and cancer groups. Yet in the past 25 years, arthritis advocacy groups are only now beginning to see the fruits of their labour. In the 1980s, advocates in the USA were successful in mobilizing nationwide support; the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) was created by Congress in 1985 with a budget of US\$ 140 million (40). A coalition of more than 35 musculoskeletal groups convenes annually to develop an agenda for advocacy and strategies to urge Congress to set higher national health priorities for arthritis care and research funding. By 2002, the NIAMS budget had risen to US\$ 448.2 million.

Until recently, arthritis advocates had little opportunity for input into setting a research agenda or the process of investigating methods to improve treatments or quality of life. NIAMS subscribes to inclusion of the patient community on advisory boards, notably the NIAMS Advisory Council. In 1998, the Director of the National Institutes of Health (NIH) established the Council of Public Representatives (COPR) to provide public input and feedback on emerging health issues and research priorities.

In 2002, patient advocates were invited for the first time to interact with leading clinical investigators working on rheumatic diseases to identify core outcomes. Researchers from OMERACT (Outcome Measures in Arthritis Clinical Trials) (41), composed of investigators from multiple disciplines (clinicians, statisticians, health scientists, radiologists, etc.) from around the world, have met regularly since 1992 to stimulate discussion about arthritis clinical trials and evaluate published evidence supporting the validity of specific outcome measures in such trials. The insights provided by patient participants confirm the value and continued involvement of advocates in future research discussions.

Corporate partnerships

In recent years, patient advocates and their organizations have been acknowledged as important stakeholders by corporations. For example, many pharmaceutical companies coordinate activities with these groups, thus creating opportunities for mutually beneficial relationships and raising the stakes for advocacy relations. Because requests from advocacy groups may surpass corporate budgets, some industries have developed strategic markers to assist their managers in prioritizing the requests most likely to yield favourable results. When considering groups with which to associate, some industries may take into account the potential investment requested, the number of company products targeting the disease, the group's goals and strategies, the group's reputation in the medical community, influence with the media, and previous track record. Similarly, advocate groups are becoming sophisticated in their search for industry partners by incorporating polished marketing strategies and tactics in their appeals.

Global partnerships: the Bone and Joint Decade 2000–2010

The Bone and Joint Decade is an example of a global, multi-disciplinary, collaborative initiative driven by a vision to unite different stakeholders for a common cause. The Decade's mission is to improve the health-related quality of life for people with musculoskeletal disorders worldwide. It is a framework organization through which patient groups, professional societies, governments and industry are working to raise awareness, empower patients, promote cost-effective prevention and treatment, and advance understanding through research. The Decade involves stakeholders from various clinical disciplines, such as rheumatology, orthopaedics, emergency medicine and trauma, sports medicine, physical medicine and rehabilitation in the areas of joint diseases, osteoporosis, back and spine disorders, severe trauma to the extremities, and disabling conditions in children (42). Since the Decade's endorsement by United Nations Secretary-General, Kofi Annan, and its launch in 2000 at WHO in Geneva, 48 governments and more than 1200 patient advocacy and health professional societies have become involved. In addition to global projects, 52 national networks have established a collaborative process to implement national action plans based on national priorities. To promote patient empowerment programmes and collaborations in developing countries, the Decade has established

regional networks to facilitate exchange among neighbouring countries. The Bone and Joint Decade demonstrates that governments, health professional societies, industry and advocate groups benefit by joining forces to leverage resources for mutual benefit — the arthritis patient is the ultimate benefactor.

Conclusion

Patient advocacy plays a pivotal role for arthritis patients and their families in today's health-care environment. The partnership between patient and health professional emphasizes the importance of the patient's experiential expertise and the knowledge/resource expertise of the health professional. Structured patient education is a cornerstone of empowerment and self-efficacy. While arthritis patient education is not yet fully integrated into management and treatment as standard practice, arthritis groups are showing their power of advocacy by mobilizing patients, families and friends into a dynamic force for societal change.

With the focus of health care in the twenty-first century on chronic diseases, patient advocacy and patient empowerment for arthritis are not only a human right but a timely necessity for our society. ■

Conflicts of interest: none declared.

Résumé

Arthrite: progrès dans la défense des droits des patients

La défense des droits des patients repose sur l'idée que tout être humain doit avoir le droit de prendre les décisions qui lui conviennent pour se soigner, justifié par la connaissance et l'expérience qu'il a de la pathologie dont il souffre. De leur côté, les groupes de défense de ces droits s'intéressent aux stratégies et aux mesures axées sur les patients. Les premiers groupes de défense des droits des patients arthritiques ont vu le jour il y a une vingtaine d'années aux Etats-Unis et ont ensuite essaimé

dans de nombreux pays. Le présent article passe en revue le développement et les conséquences de la défense des droits de la personne et l'évolution récente, dans la Région Asie-Pacifique, en Europe et en Amérique du Nord, des groupes mobilisés pour la sensibilisation aux problèmes d'arthrite, pour la recherche, les partenariats avec le secteur privé et pour l'initiative mondiale de la Décennie de l'os et de l'articulation.

Resumen

Artritis: progresos en la defensa de los intereses de los pacientes

La defensa de los intereses de los pacientes parte de la premisa de que las personas tienen derecho a hacer sus propias elecciones respecto a su atención de salud. La defensa de los intereses personales se centra en la experiencia práctica del individuo afectado por la dolencia, mientras que la defensa de los intereses de grupo se basa en estrategias y acciones centradas en los pacientes. Los primeros grupos de defensa de los intereses de los enfermos de artritis se establecieron hace más de 20 años en

los Estados Unidos, y posteriormente se han extendido a muchos otros países. En este artículo se examinan el crecimiento y el impacto de la defensa de los intereses personales y las últimas novedades en materia de defensa de intereses de grupo en la región de Asia-Pacífico, Europa y América del Norte por lo que se refiere a la concientización sobre la artritis, la investigación y las alianzas con empresas en ese terreno, y la iniciativa mundial de la Década de los Huesos y las Articulaciones.

Arabic

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