doi: 10.1111/j.1369-7625.2008.00499.x

Patient organizations in Finland: increasing numbers and great variation

Hanna K. Toiviainen PhD MSc,* Lauri H. Vuorenkoski MD DMedSc† and Elina K. Hemminki MD DrPH‡

*Senior Officer, †Development Manager and ‡Research Professor, STAKES National Research and Development Centre for Welfare and Health, Health Services Research, Helsinki, Finland

Correspondence
Hanna Toiviainen
Senior Officer
National Supervisory Authority
for Welfare and Health
Finland
Lintulahdenkuja 4
P.O. Box 210
FI-00531
Helsinki
E-mail: hanna.toiviainen@valvira.fi

Accepted for publication
29 February 2008

Keywords: health consumer groups, health policy, non-governmental organizations, patient organizations

Abstract

Objective There is very little research on patient organizations (POs), even though their numbers and influence seem to be increasing. The purpose of this study was to describe the establishment, membership, size, organization, decision making and basic funding of national POs in Finland.

Setting and participants National POs ($n = 130$) were identified from their umbrella organizations and by Internet searches. Data were collected from POs' web pages (87% of POs had one), Finland's Slot Machine Association (RAY, an important public financier of POs), a relevant survey done by a local TV-company, and interviews and written materials of POs.

Results and conclusions Some current national POs were established around the turn of the 19th century. The rate of establishment of new POs increased from the 1970s and particularly in the 1990s when POs were characterized by increasing specialization. POs focused on different patient groups and diseases and were founded by philanthropists, physicians, patients, parents and the drug industry. Members could be patients, patient relatives, health-care professionals and organizations. POs widely varied in memberships (20–145 000, in 2002) and in number of paid personnel (0–1395, in 2002), organizational structure and decision making. Interest groups and financiers were often represented in decision-making organs. Activities included mutual support and service production, and, increasingly, informing and lobbying. POs had wide domestic and international co-operation and networking. Drug industry marketing was visible on PO web pages. Budget sizes varied (4000–15 million euros, in 2001). The main public financier was RAY. The old national POs were large and part of national social and health care, but newer ones were often established for mutual support and lobbying. National POs are not uniform but characterized by great variation. The number of national POs is increasing suggesting tighter competition for financing and visibility in the future.

Introduction

Organized action by patients and potential users of health services can be seen in many health and social welfare non-governmental organizations (NGOs). Broader health movements have recently got scholarly attention.[1,2] More specifically, a 'patient organization' (PO) is used to indicate a group focusing on specific diseases and use of health services. Definition of a PO is not unambiguous and the border to health activist and self-help groups is sliding.

Patient organizations are often seen in contrast to the official health care system. However, especially in the Nordic countries, Finland included, national social and health policies, voluntary organizations and the state have operated side by side. Voluntary NGOs have been quite visible in the Finnish health care system which is much decentralized. More than 400 municipalities have the responsibility to provide and fund public sector health services. Primary care services are normally provided by municipality owned health centres and secondary services by hospital districts which are federations of municipalities. The public can influence decision making in the health system directly at a local level through municipal councils and municipal health committees which represent the populations of their municipalities and which are responsible for the management of health services. Hospital districts have council and executive boards, which are politically elected by municipal councils.

The most important public financier of Finnish health and social welfare NGOs, including POs, has traditionally been Finland's Slot Machine Association (RAY). It was established in 1938 by the organizations themselves for the purpose of fund distribution for themselves. From its beginning, RAY has been governed by the state, though member organizations are represented in its decision making. The highest authority is used by the General Meeting, which is held once a year, and in which the state and the member organizations are represented. The state has a key role and the organizations are in a secondary position in using decision-making power. Membership of RAY is neither a prerequisite nor guarantee for getting funding. RAY has the exclusive right to operate slot machines and casinos in Finland. It distributes the profits to associations and foundations working for the public good and aiming to promote health and social welfare.

It has been estimated that in the mid-1990s, some 1.5 million people have membership in the health and social welfare NGOs in Finland,[3] out of a population of 5.2 million. However, there is very little research of the Finnish NGOs or POs. Literature consists mainly of histories, anniversary books and undergraduate thesis,[3] focusing on one organization,[4] or economic aspects,[5] and available only in Finnish. Likewise, in other countries we found only two comprehensive studies of POs as a system: one from the UK[6–9] and the other a comparison between the USA and the UK.[10] These studies described POs and their role, showing increasing numbers over time and an expanding area of action.

Our observations and anecdotes led us to hypothesize that in Finland the number and influence of POs has recently increased. Thus, we wanted to study: (1) which existing POs have been established at different times and on whose initiative? (2) Who are the members of POs? (3) What size, organization structure, administration and decision making do POs have? (4) What do POs do and what co-operation do they have? (5) Where does their basic funding come from?

Methods

Identification of POs

In Finland, there is no clear-cut definition of a PO and no list of non-governmental organizations (NGOs) in the health field. We started by defining POs using three guiding criteria: a PO is a registered organization (Register of Associations) that has been formed around a specific and officially accepted disease or disability (e.g. in ICD-10-classification); a PO itself claims to be a PO or has sick people or their family as members and a PO is nationwide (may have registered local associations as members).

Many Finnish health and social welfare NGOs are organized under five national umbrella organizations and we used their web pages as the basis for creating a list of national POs. These umbrella organizations are overlapping and a PO may belong to several of them. The umbrella organizations are: the Finnish Slot Machine Association (RAY), the Finnish Federation for Social Welfare and Health (STKL), the Finnish Centre for Health Promotion (TEK), the Finnish Patients' Union (FPU) and the Association of Voluntary Health, Social and Welfare Organizations (YTY). Additionally, the web pages of Sosternet were used; Sosternet is a net-based information service by social and health organizations, with STKL, TEK and YTY as members, and funded by RAY. Once national POs from the umbrella organizations were identified, further links found on the national PO web pages provided new names of potential POs and their web-addresses. In cases where it was not clear whether it was a PO or not, further information was sought via Google.

We found 390 health and social welfare NGOs (Fig. 1). We excluded NGOs focusing on social welfare, leaving 283 health-related NGOs. Of them, 28 organizations were dropped out from the final data as 'borderline cases'. Of the NGOs, we identified 130 specific POs, including the Finnish Patients' Union (a general organization having individual citizens and small POs of rare diseases as members).

Our definition of POs worked well in practice. Almost all (95%, $n = 124$) of the 130 national POs also identified themselves as POs. Six did not explicitly classify themselves as POs: three were organizations for parents of sick children and three were mental health organizations. Of the 130 national POs only a minority belonged to the five national umbrella organizations or Sosternet, used as a starting point to identify POs.

Data collection

Information on the POs was collected from different sources: national PO web pages, RAY, a relevant survey by a TV-company, and interviews and written materials of national POs.

National PO web pages were studied from June to September 2002. Certain basic information (see Results) was systematically collected in numerical format and various descriptive data in text form. In total, we found web pages for 113 national POs (87%) (Fig. 1). The extent and quality of web pages noticeably varied.

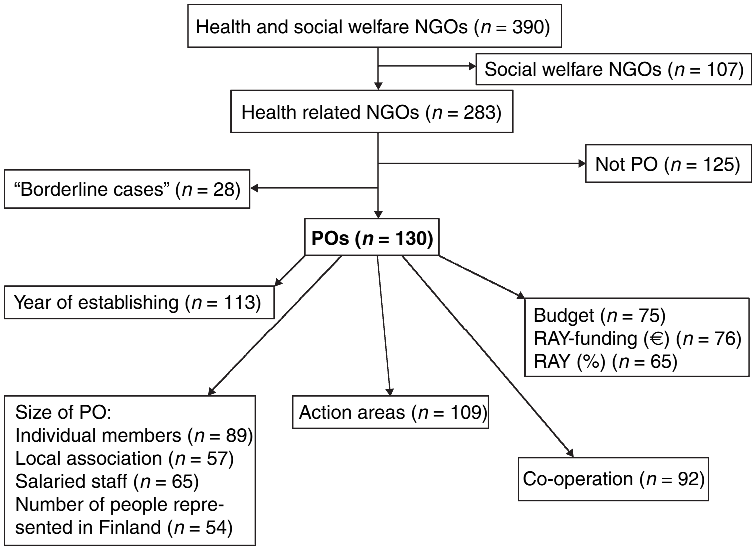

Figure 1 Identification of national patient organizations (POs) and data available. NGO = non-governmental organization, PO = patient organization, RAY = Finnish Slot Machine Association. Action areas = informing, supporting, lobbying, service producing and research.

The electronic files of RAY included information on organizations which had applied for funding for the year 2002. It included POs' annual reports and budgets for 2001 and action plans and budget proposals for 2002. We received such kinds of information for 76 (58%) of our 130 national POs. Data were received from RAY as an EXCEL file and we adapted and transferred them to our database. In addition, one researcher (HT) had informal discussions with two RAY employees dealing with PO funding.

In October 2003, a commercial TV-company (MTV3-Finland/News) carried out an e-mail survey of 85 POs. It consisted of a one-paged structured questionnaire with a 1-week reply time; the sample was compatible with our list of national 130 POs and missed only small and lesser known national POs. The response rate was 65% (*n* = 55, of which 54 fulfilled our criteria of a PO). The survey was investigative journalism and the aim was to study the co-operation of POs with the drug industry. After hearing of the survey, we approached the company and were able to receive the original questionnaires. We coded the open questions and added the data to our database. For this article, we used only basic information about POs' background to complete the information derived from the web pages and RAY.

Between April and June 2004, semi-structured interviews were made with and written material collected on 13 national POs of different aged and sizes and related health issues so as to analyse their interaction and co-operation with other health care actors. The informants in the interviews were the highest paid staff available[11] or chairpersons[2] of the highest decision-making organs. These interviews were used to fill in information about issues which had arisen earlier.

Analysis

Quantitative information was collected on an SPSS-database. If the quantitative data from different data sources varied, RAY was defined as the primary source, web pages as the secondary and the MTV-survey as the third. The MTV-survey was used to estimate how many ill people in Finland were represented by specific POs. Web pages, discussions with experts in RAY and interviews with and written materials of national POs constituted further qualitative data.

An expert group (authors and one extra physician researcher) classified POs to seven groups using the associated health problem as the starting point. Some POs could have been classified to several groups. After five discussion rounds, each PO was included to one group by the following rules: Firstly, all organizations for children and/or their parents formed one group ('children & parents'). From the remaining, organizations for people with disabilities formed one group ('disability') and patients having diseases with strong genetic cause ('genetics') another. From the remaining organizations patients having neurological diseases ('neurology') and mental health problem ('mental health') formed a group each. Next, we separated organizations for patients having diseases with significant public health importance (for example, 'common diseases' such as tuberculosis, cancer, rheumatism, diabetes, polio, heart disease, allergy and epilepsy). The rest of the organizations were placed in the group 'other'.

Cross-tabulations were formed where information was available from over 50% of the POs. The chi-square test and Fisher's exact test were used to test the statistical significance of the cross-tabulations. Pearson correlation coefficients were calculated to study the relations between continuous variables.

Results

Establishment of POs

The oldest of the current POs was established in 1897 and three others were established at the turn of the 20th century (Fig. S1). After this no POs were established for over 20 years (1908–29). During the 1930s, new POs again began appearing and between 1940 and 1969 the number increased steadily (ranged from five to seven new POs per decade). A clear growth started at the beginning of the 1970s and about

Table 1 Numbers of national patient organizations (n = 130) by group and period of establishment, % (n)

	1897–1969	1970–89	1990–2002[1]	Total[2]
Children and parents	16 (4)	21 (9)	22 (11)	22 (29)
Disability	40 (10)	17 (7)	18 (9)	22 (29)
Genetics	0 (0)	7 (3)	6 (3)	5 (7)
Neurology	8 (2)	14 (6)	8 (4)	9 (12)
Mental health	4 (1)	7 (3)	14 (7)	8 (11)
Common diseases	28 (7)	2 (1)	0 (0)	6 (8)
Other	4 (1)	31 (13)	32 (16)	26 (34)
Total	100 (25)	100 (42)	100 (50)	100 (130)

[1] Those identified by 10th of September 2002.
[2] Includes 13 patient organizations with missing year of establishment.
Source: web pages, RAY-files.

40 POs were established during the next two decades. Between 1990 and 2002 the establishing of new POs was very active (50 new POs) (Source: web pages, RAY-files).

Table 1 shows the current POs by classification of health problem and establishment period. The first organization was the Finnish Association for Mental Health, established in 1897. The next POs (established in the first decade of the 20th century) were organizations for blind and deaf people. Organizations for other disability groups started to be established during the 1930s and increasingly after the Second World War. Organizations for common diseases were established between 1930 and 1969. The first organization for parents of sick children – the Finnish Association of Parents of the Deaf – was founded in 1963. The first POs for patients having a disease of mainly genetic origin were established in the 1970s while POs of the 1990s were mainly for specific conditions in the 'old' areas (e.g. disabilities of chromosomal disorders, cancer and skin diseases), as well as some new diseases. Some organizations are solely for Swedish-speaking people (and families of sick children) while in some cases disease or condition (e.g. as a result of personal conflicts or drug industry initiatives) would have more than one PO (Source: RAY-files and discussions, interviews and written material).

The occasional short histories of the POs on their web pages showed that the oldest POs were based on charity and were founded by wealthy benefactors. Physicians later had a significant role in establishing POs. In the 1960s and 1970s, patients themselves as well as parents of sick children were active. Of the most recent POs, established since the 1990s, some have been jointly established with drug companies (Source: web pages, interviews and written material).

Some POs have changed their name, especially since the 1990s. Usually the change has been away from disease-specific words to more neutral terms, with the word 'health' often included for example (Source: web pages).

Size, organization and decision making

Information on the number of individual members was available for 89 of the 130 POs (see Table 2). For these 89, the total membership was 665 000 persons; the mean number was 7466 and the median 1055. The range was large: 7% of the 130 POs had less than a hundred members, 25% some hundreds, 26% some thousands and 11% some tens of thousands of members (total range from 20 members to 145 000 members). The older the organization was, the more individual members it had ($r = 0.47$, $n = 89$). The largest POs were the Cancer Society of Finland (with about 145 000 individual members), the Finnish

Table 2 Distribution of national patient organizations by number of individual members (size) and period of establishment, % (n)

Size[1]	1897–1969	1970–89	1990–2002	Total[2]
Small	12 (3)	29 (12)	32 (16)	24 (31)
Medium	24 (6)	36 (15)	20 (10)	24 (31)
Large	56 (14)	24 (10)	6 (3)	21 (27)
No information	8 (2)	11 (5)	42 (21)	31 (41)
Total	100 (25)	100 (42)	100 (50)	100 (130)

[1] Small < 500, medium 500–2999, large ≥3000 members.
[2] Includes 13 patient organizations with missing year of establishment.
Chi-square test: $X^2 = 18.5$, d.f. = 4, $P = 0.001$.
Sources: web pages, RAY-files (establishing year); web pages, RAY-files, MTV (number of individual members).

Heart Association (83 000 members) and the Finnish Rheumatism Association (54 000 members).

Some POs were liberal in accepting members: all those who were interested in joining, including individuals and institutions, were welcomed. Usually, individual members were 'ordinary members' with a right to vote, while institutions were 'support members' without a right to vote. Other POs put restrictions on their membership, such as accepting only sick people and relatives living in the same household as regular members, with others accepted only as support members. On the other hand, there were also a few POs in which different institutions were regular members and individuals had the possibility for only support memberships. POs established between 1970 and 1989 had the most varied types of membership (see Table S1). Of the 130 POs, 12% (n = 16) had other national POs as institutional members (Source: web pages).

The POs' own estimations of the number of Finnish people who suffer from the condition which they represented (available for 54 out of 130) were many times higher than the numbers of current members. The mean number was a quarter of million (257 502) and the median 35 000 patients (Main source: MTV). Again, the range was large: the largest estimation being 1.5 million patients (the Allergy and Asthma Federation) and the smallest estimation being 150 patients. The total estimation of people affected based on the information of the 54 POs was 14 million (Source: web pages).

A multi-storey, hierarchical, 'umbrella' structure was typical for POs: a central organization at national level, then regional associations and local associations as the smallest units. Of the 130 POs, 40% (n = 57) had regional associations. The mean number of local associations per PO was 42 and the median was 16; the range was large, from 2 to 238. However, some POs had only a national central organization in which people had membership; this applied especially to smaller POs. Besides the central offices/headquarters some POs had regional or local offices and contact persons. Staff included physicians, accountants, journalists and patients (Source: web pages, RAY-discussions).

POs employed salaried full- and part-time personnel and also volunteer workers. Information on the paid staff was available from 65 POs, and the number of their employees totalled together 4199, giving a mean of 65 and a median of 5. But, the range was again large, from 0 to 1395 persons (Main source: RAY). The large POs in particular used salaried staff but smaller POs could be totally voluntary-based (Sources: web pages, RAY-files).

Patient organizations for common diseases were large and complex in size and type of membership, staffing and in their decision making. The structures have become more complex and bureaucratic with established and widening activities. Typically, POs had two kinds of decision-making organs: one with democratically selected or elected representatives of individual members and on the other with appointed representatives of interest groups and financers. The latter group often included experts such as physicians (often specialists and/or in leading positions of the special field), parliament members (from some parties or sometimes evenly from all parties) and business representatives. Large-scale representation was seen specifically in large POs and was not constant. In large POs, policies were made by the democratic organ, which gathers regularly at between 6- and 24-month intervals. That organ represented ordinary members. Implementation decisions were made by a council or a board of directors which met more often than the democratic organ. In smaller POs, the council acted both as a policy and as a decision-maker. Different committees with concrete projects met several times a year. Furthermore, POs consulted their constituencies as experts, such as patients, physicians, politicians and representatives of business (Source: web pages).

Activities and co-operation

Detailed information on activities was available from 109 of the 130 POs (see Table S1). POs were innovative and many current tasks of the official health and social welfare system were originally started by them. Activities were connected to the social questions and changes of different times in the society. A 'sickness-based' action arena had changed towards more general public health field. *Mutual support* operated at an individual level, often in local chapters, where people with similar experiences shared their expertise of everyday life. *Service production* included health care, social and rehabilitation services (e.g. different courses). *Information sharing* included information to members as counselling and for society as awareness rising. *Lobbying* happened in many ways. POs were 'watch-dogs' of official services, speaking out both for and against it. In the last 20 years, POs have pushed for insurance legislation and drug reimbursements. For example, three POs specifically mentioned in their web pages that they lobbied in regard to drug reimbursement issues. A quarter of the POs were engaged in research, either their own (e.g. surveys of members) or through separate research charities. All activities were more common in older and larger POs (Table S1). All old POs provided services.

Many POs had an organized relationship with political decision-makers, such as parliament members. The relationship with politicians did not depend on the POs' size, with some smaller POs also organizing relationships with politicians. Some POs had formed or aimed to form a network for their disease within parliament. Some POs only wanted to have politicians who had personal or close experience of the disease (Source: web pages, interviews).

In their web pages, some POs mentioned drug firms and other companies as their support members or as co-operation partners. Others named co-operation products (e.g. foodstuff, cleaning equipments, textile and aid equipments), joint projects and joint conferences.

The web pages of new POs as well as those of some older POs showed that voluntary work from home, without separate premises, was typical in starting a new PO. The first tasks were information collection and distribution, educating support persons, creating local networks, fund-raising and seeking contacts to health-care professionals. To get funds from RAY, increasing the number of members became important. Voluntary work has a central position and only later do they take on paid employees. The first salaried employee was usually a secretary, while separate premises, an executive manager and other employees typically came later.

Some POs were members of national health and social welfare umbrella organizations. These organizations were mediators between POs and government and allowed co-operation between POs. Typically, POs could give a joint statement through them (Source: web pages, RAY-discussions, interviews and written material).

Patient organizations also engaged in other domestic or international co-operation (Table S1). Information on such co-operation was available from 92 of the 130 POs. Co-operation included memberships in administering bodies of other organizations or informal networking. Co-operation with other POs and the public sector were common and was aimed at increasing resources and influence.

Patient organization web pages carried implicit advertising of health technologies. There were links to specific products (though not drugs) and to drug firms or other medical technology companies or to commercial patient information and disease risk tests pages. Some POs provided counselling by telephone, but it was not always clear whether it was free or who financed the service. It was often mentioned that the counselling person was a health-care professional. In some cases, it was mentioned that counselling was sponsored by a drug firm. The drug industry also educated physicians and nurses alone and together with POs (Source: web pages, interviews and written material).

Besides national co-operation, 45% (n = 58) of the 130 POs engaged in international co-operation as mentioned on their web pages (Table S1). National co-operation did not depend on the age of a PO, but international co-operation increased by age of PO (Table S1). Likewise, international co-operation was more common among larger than smaller POs.

Table 3 Distribution of national patient organizations (POs) by the size of budget (€) and RAY-funding (%) in 2001, by period of establishment of the organization

	1897–1969[1] (n = 23)	1970–89[1] (n = 31)	1990–2002[1] (n = 21)	Total[2] (n = 75)
< 100 000	12 (3)	24 (10)	34 (17)	23 (30)
100 000–1 m	16 (4)	31 (13)	8 (4)	16 (21)
> 1 m	64 (16)	19 (8)	0 (0)	18 (24)
No information	8 (2)	26 (11)	58 (29)	42 (55)
Total	100 (25)	100 (42)	100 (50) [3]	100 (130)
Mean (SD), ×1000, €	3546 (3720)[3,4]	964 (1822)[4]	130 (129)[4]	1642 (2797)[3,4]
Median, ×1000, €	2863[3]	246[4]	76[4]	253[4]
Minimum, ×1000, €	16	19[4]	4[4]	4[4]
Maximum, ×1000, €	58 306	9336	494	14 848
RAY-funding				
Mean (SD), %	55 (25)	70 (26)	71 (20)	65 (25)

[1] POs with 0 € budgets were excluded (one PO in 1897–1960 and 1970–89 and eight in 1990–2002).

[2] Includes 13 patient organizations with missing year of establishment.

[3] Chi-square test: $X^2 = 34.4$, d.f. = 4, $P < 0.001$. Class ‘No information’ excluded.

[4] An association with very large budget (58 300 €) was excluded.

Funding

Information on budgets for 2001 was available from 75 of the 130 POs. The total budget of these POs was EUR 163 million and variation was large (Table 3). Roughly, the older a PO was the larger the budget ($r = 0.66$, $n = 74$). Likewise, the more members the organization had, the larger the budget it had ($r = 0.49$, $n = 68$). Seven out of the ten POs with zero budgets had been established during the previous 10 years (Source: RAY-files).

About half of the 130 POs got RAY funding in 2001 (52%) and in 2002 (54%). The older the organization was, the smaller the relative proportion of RAY funding ($r = -0.351$, $n = 65$), while the more members the organization had, the smaller the proportion of RAY funding ($r = -0.48$, $n = 64$), Table 3 (Source: RAY-files). Some POs, especially smaller and newer ones, mentioned that they had applied for funding from RAY several times but had not received any. It was also reported that filling forms for RAY is difficult and time-consuming. POs were expanding their funding sources. There were several other public funding sources, such as the Ministry of Health, the National Insurance Institution, the Health Promotion Centre, cities and municipalities. A new financier was the European Union Commission. Members of the FPU received their funding from it. Some POs revealed nothing about their financing on their web pages (Source: web pages, interviews).

Private funding sources included membership fees, profits from selling products and organizing courses, journal subscriptions, advertisements, donations and profits of savings and investments. Some large POs also had property portfolio. Some had established foundations to support the organization’s activities. Membership fees were an important source of income. Support and institutional membership fees were, at least in some of the POs, higher than ordinary individual membership fees (Source: web pages, interviews).

Discussion

The number of national POs is increasing. National POs are not a uniform group of organizations but are rather characterized by great variation in terms of initial establishment, organization, activities, and funding as well as to age, the size of membership and the specific health issues concerned.

Our purpose was to give an overall description of the Finnish national POs as they were in early 21st century. We do not have information of POs which stopped their activities before 2006, but their number is believed to be small. Our method to identify the POs succeeded very well, but we may have missed some new POs or those without an Internet presence. The data consisted of several information sources of which the web pages were the new research method. After identifying the POs, we used the most exact quantitative information available and conducted interviews to fill in gaps and examine issues which had risen earlier.

Establishing of POs

The establishment and increase in the number of PO since the 1980s is in line with the development of POs in the UK[7–9] and the USA.[10,11] Our recent observations show new POs have been established since our data collection. Different societal and health care developments (e.g. hygiene improvements, the Second World War, industrialization, recession, legislative changes, etc.) have been connected to the birth of POs' in Finland. Likewise, in the USA[10] and UK,[7,9,10] the early roots of POs were in philanthropy and war experiences. Carroll[11] has reported that in the USA large public health organizations for common diseases were established before the radicalism of the 1960s. Later, POs for more rare diseases were established and then POs for new health problems and specialized diseases were established.[11] At the turn of the 1990s, Finland met with an economic recession and services weakened. The state subsidy system changed in 1993 and in the latter part of the 1990s mental health was elevated on the public health agenda. Furthermore, the medicalization increased, and availability of new technologies and diagnostic methods has at the same time continued. These social changes correlate with the increasing number of mental health POs and with the increasing number and specialization of POs in general.

In the UK, following on from the work of philanthropists, initiatives for establishing POs came from professionals,[12] followed later with initiatives by citizens and service users and parents in both the UK[7,12] and Australia,[13] and later still by patients themselves.[7,8,12,14] In the USA and UK, organizations that were initially voluntary have changed first to semi-professional and then to totally professional organizations within few years.[10] In Finland, some POs have been led more by professionals than lay people since their inception. Recently in the UK, people with personal experience of disease have established organizations emphasizing mutual support and services.[7] Wood[10] has argued that with changing motives and names, and through widening areas of activity, POs are reflecting the development of medicine in general. This medical modernization is seen in POs.[15] Having several POs focusing on the same diseases can be explained variously through different caring philosophies, competition, personal conflicts and industry links.

Structure of POs

Even though information was not available from all POs, the numbers of individual members as well as PO estimations of people who suffer from the conditions represented were large: the number of estimated sick people was 2.7 times higher than the actual population of Finland. This may partly be explained by co-morbidity or by some people belonging to several POs. It may also be a result of exaggeration; such large numbers may be used to indicate an important public health problem thus raising the importance and visibility of PO's activities.

Lofgren[13] has argued that growth of a PO (e.g. including their total number, member numbers, staff, activities, economical meaning, etc.) is seen as the norm in the current consumerism in health care. In Finland, differences in member size were extensive: there were POs that were both larger and smaller than those found in the UK.[8] In the UK and USA, some organizations which claim to represent patient issues are completely without a membership or patients,[10] but we included in our study only POs with patients and individual members (some also had other members). In the USA, medical professionals and their associations are more often POs' members than in Finland.[8] However, especially physicians were members also in Finland. Also in the UK organizational structure varied according to the POs' age.[7] In the USA, most POs did not have local organizations, while some organized only at local level, and some only at international level.[10] In Finland, POs have used salaried staff for decades while the number of volunteers has been relatively low. POs' multiform personnel structures may create a picture of strong professionalism which may improve their reputation in health politics.

Activities and co-operation

Patient organization activities found in Finland (see earlier) have also been reported in the UK,[7–9] the USA,[10,16,17] Australia,[13] and Canada,[18,19] but while research has had a prominent position in PO policy in these countries,[13,18,20,21] the same has not been true in Finland.

Kuotola[22] has divided the different stages of PO life cycles into stages of inspiration, pressure politics, professionalization, cabinet politics and 'monument politics'. Halinen[23] has divided the stages into the politics of 'position formalization', development of hierarchy and normalization. Lofgren[13] has argued that many POs of the 1960s were established as pressure groups. The 'challenging role' (influencing, lobbying) has received more emphasis especially since the 1990s, when the number of POs began to increase.[10,15–17,24–27] In the USA and UK, lobbying for legislative changes has occurred especially by POs working for neurological diseases, genetic diseases and AIDS and by organizations for parents of sick children.[7,8,10,12]

Besides mutual support and service production, all activities of POs may be seen as political, aimed at influencing society, the health system, officials and health politics (decision-makers, providers, payers), for example, through raising patients' expectations and demands. From the perspective of a consumer movement, the web pages of POs make it possible to consider, also for patients and consumers, what information and services POs provide, what the information is based on and wider links the organization has in the form of hyperlinks. Shared influencing based on co-operation started in the 1990s may be seen as networking with other stakeholders. Networking means centralizing resources, widening support and pressure and utilizing 'mass power'.

In the British study, 85% of the POs had different coalitions through which co-operation was made with decision-makers, government, professionals and business.[7–9] In international studies, coalitions in mental health field and breast cancer field have been successful.[28,29] Crossing national borders is an international phenomenon. US-based organizations are establishing offices in Europe and financing different activities with the aim of getting patient groups to promote activities (e.g. research, education, screenings and treatments) in their home countries.[30] The European breast cancer movement – which acts in over 20 countries and has a representation in the European Health and Patients Forum – connects patient and professional associations internationally.[31,32] It has recently started to act in Finland with the support of a drug firm. Because of Finland's geographical position and small population, international trends may influence PO activities in Finland more than vice versa.

Funding

Even though information was not available for all POs, the combined budget of those we had information on was 1.6–1.7% of the Government's total health care expenditures in Finland (9456 million € in 2001 and 10 207 million € in 2002[33,34]).

RAY-funding appears to be central, especially for new and small organizations. However, to be eligible for RAY-funding, the POs' activities must be established. The funding has traditionally been given for projects and services, though not for basic structure. Recent changes in European Union competition legislation services has meant that services which bring profits are considered as business activity; services supported by RAY funding cannot be services that are also offered for sale by companies. Thus, the POs' traditional role as producers of services may be in danger to some extent.

Developing professionalism also creates a reciprocal dilemma. The professional touch is needed to make a convincing case to officials, for processing projects, producing services and for obtaining funding. At the same time, POs are often reminded about their traditional mutual support role. Both co-operation with the commercial sector[35] and the developing of professionalism may impinge on a PO's position as a grass-roots level citizen organization. In the UK, funding problems are similar to Finland (e.g. the difficulty of obtaining public funding for basic administration and complex application procedures that require time and expertise to complete).[7–10,12] The UK study also reported public funding was sometimes dependent on POs' support for governmental policy and on coalitions with health professionals and commercial interests. The state support for POs is important also in the USA, even though its health care system is largely based on private insurance.[10]

Who are POs representing?

Patient organizations' decision-making organs include physicians, politicians and representatives of business. Further, POs consult same groups as experts. The large Finnish national POs work like enterprises (having large decision-making organs, networks, interest groups, coalitions and consultations with experts). Rolstad[21] has argued that some POs have eliminated all medical professionals from their membership and governing but use boards of medical professionals as advisors. Some do not give voting rights to physicians and others do not accept physicians for ideological reasons.[8] In Finland, there has been little discussion about the representation of physicians or other health-care professionals (e.g. nurses) in POs, although there has been discussion about the relationship between physicians and the drug industry, and the drug industry increasingly educates nurses as well as doctors, both alone and together with the POs. In Canada, nurses have already established some POs.[18] In the UK and USA, where POs led by medical professionals are the most influential, POs promote specific fields of medicine and make decisions on research funding,[7–9] usually to such institutions who are also representatives in the POs' administration organs.[10] In such matters, the POs' ability to represent the interests of patients has been curtailed.[12,36,37] Warnings have especially been made on co-operation between research-oriented physicians and industry physicians.[10,38]

In Finland, POs have traditionally been considered to represent objectivity, independence, the common or specific 'good' and the patient's best interest in social realm, with clear activities and boundaries. The old POs are seen mainly through their mutual support and service production roles in health care and health policy discussion in Finland. Large POs, such as public health POs, are more organized and professional-led while the small ones work more on a voluntary-basis. Currently, many POs and other health-care actors (e.g. associations of medical professionals, the drug industry) seem to have their own and separate economic and other interests as well as having shared orientations. The concept of the PO is expanding and fragmenting, while the boundaries are blurring. The relations of the POs with other actors have become more complex and ambivalent.[13] In Europe, co-operation between the European Patients' Forum and industry has been questioned.[39] In the UK, a House of Commons Committee has included POs in a report on the influence of the pharmaceutical industry in society.[40]

Recently, it has been suggested within the international research literature that POs could be viewed as a consumer movement that potentially 'challenge' health care. Concepts such as health social movement and consumer groups or organizations or movements have been used. The terms include the idea of a new social movement for which consumerism and activism are connected. At least in the Anglo-American context, consumerism in health care and increasing patient activism since the 1990s have been seen as a new consumer phenomenon.[7,25] Patients' consumer role and status have increased through the rhetoric of choice and the politics of consumer rights.[10] Patients are developing lay expertise on their own situation and want to make decisions about their own treatment.[7,41] In Finland, the Act on Patient Status and Rights came into power in 1993. The Finnish Patients' Union is a member of the Finnish Consumers' Association and both act together and also separately on health matters. The discussion on patient 'participation' has just been started but not extended so much to the 'consumer' context. The number of POs is increasing which suggests tightening competition for financing and visibility. POs are enlarging their funding sources. There is a danger for blurring boundaries and implicit advertising already seen in POs' web-pages. Co-operation with markets endanger POs' image as grass-root level citizen organizations.

In the future, the financing of POs, the position of technology in their marketing for example, and their relation to drug companies and other industries is going to be an important area for research. More analysis is also needed on co-operation between POs and the interaction between different actors and roles in health policy development.

Acknowledgements

We thank Finland's Slot Machine Association and MTV-Finland/News for their co-operation and Merja Autio, Outi Räikkönen, Tiina Sevon and Sirkku Vuorma for technical support. The research was financially supported by the Ministry of Education (The National Post Graduate School in Social and Health Policy, Management and Economics and Doctoral Programmes in Public Health) and STAKES. There are no conflicts of interest.

Supporting information

Additional Supporting Information may be found in the online version of this article:

Fig S1. Cumulative number of current (existing in September 2002) national patient organizations (POs) by year of establishment (1897–2002) (missing data $n = 13$). Before 1950: 12 POs, < 1970: 25, < 1980: 44, < 1990: 67, < 2000: 108, 117 < 9/2002. Source: web pages, RAY-files.

Table S1. Proportions of national patient organizations by type of members, action area and co-operation and by period of establishment, % (*n*)

References

1 Special issue: patient organisation movements. *Social Science and Medicine*, 2006; **62**.

2 Health social movements: special issue. *Sociology of Health and Illness*, 2004; **26**.

3 Rönnberg L. Hyvinvointi ja kolmas sektori. In: Kinnunen P, Laitinen R (eds) *Näkymätön kolmas sektori*. Helsinki: Sosiaali- ja terveysturvan keskusliitto, 1998: 10–22.

4 Poteri R. *Meissä on ytyä! Selvitys valtakunnallisten sosiaali- ja terveysjärjestöjen toiminnasta*. Helsinki: Sosiaali- ja terveysjärjestöjen yhteistyöyhdistys YTY ry, 1998.

5 Helander V, Laaksonen H. *Suomalainen kolmas sektori. Rakenteellinen erittely ja kansainvälinen vertailu*. Helsinki: Sosiaali- ja terveysturvan keskusliittto, 1999.

6 Baggott R, Allsop J, Jones K. *Speaking for Patients and Carers. Health Consumer Groups and the Policy Process*. Great Britain: Palgrave Macmillan, 2005.

7 Allsop J, Jones K, Baggott R. Health consumer groups in the UK: a new social movement? *Sociology of Health and Illness*, 2004; **26:** 737–756.

8 Allsop J, Baggot R, Jones K. Health consumer groups and the national policy process. In: Henderson S, Petersen A (eds) *Consuming Health. The Commodification of Health Care*. London, USA, Canada: Routledge, 2002: 48–65.

9 Jones K, Baggott R, Allsop J. Influencing the national policy process: the role of health consumer groups. *Health Expectations*, 2004; **7:** 18–28.

10 Wood B. *Patient Power? The Politics of Patients*' Associations in Britain and America. Buckingham, Philadelphia: Open University Press, 2000.

11 Carroll D. Self-help and the new health agenda. *Social Policy*, 1994; **24:** 45–52.

12 Hogg C. *Patients, Power & Politics. From Patients to Citizens*. London, Thousand Oaks, New Delhi: Sage Publications, 1999.

13 Lofgren H. Pharmaceuticals and the consumer movement: the ambivalences of ‘patient power’. *Ausralian Health Review*, 2004; **28:** 228–237.

14 Petersen A, Kokanovic R, Hansen S. Consumerism and mental health care in culturally diverse society. In: Henderson S, Petersen A (eds) *Consuming Health. The Commodification of Health Care*. London, USA, Canada: Routledge, 2002: 121–139.

15 Hess DJ. Medical modernisation, scientific research fields and the epistemic politics of health social movements. *Sociology of Health and Illness*, 2004; **26:** 695–709.

16 Klawiter M. Breast cancer in two regimes: the impact of social movements on illness experience. *Sociology of Health and Illness*, 2004; **26:** 845–874.

17 Kolker ES. Framing as a cultural resource in health social movements: funding activism and the breast cancer movement in the US 1990–1993. *Sociology of Health and Illness*, 2004; **26:** 820–844.

18 Ellis KM. The Brain Tumor Foundation of Canada: the role of facilitators for its support groups. *Axone*, 2000; **22:** 10–12.

19 Waller M, Batt S. Advocacy groups for breast cancer patients. *Canadian Medical Association Journal*, 1995; **152:** 829–833.

20 Rabeharisoa V, Michel C. The involvement of patients’ associations in research. *International Social Science Journal*, 2002; **54:** 57–65.

21 Rolstad T, Zimmerman G. Patient advocacy groups. A key prescription for dermatology. *Dermatology Clinics*, 2000; **18:** 277–285.

22 Kuotola U. *Vammaiset ja yhteiskunta*. *Sosiaalihuollon näköaloja*. Reino Salon juhlakirja: Tampereen yliopisto, 1981.

23 Halinen I. *Ruohonjuuritasolta dynaamiseen imagoon? -Aids-tukikeskuksen kehitysvaiheet kolmannen sektorin näkökulmasta*. Terveystieteen laitoksen julkaisuja 4, Finland: University of Tampere, 2000.

24 Beard RL. Advocating voice: organisational, historical and social milieux of the Alzheimer’s disease movement. *Sociology of Health and Illness*, 2004; **26:** 797–819.

25 Braun L. Engaging the experts: populari science education and breast cancer activism. *Critical Public Health*, 2003; **13:** 191–206.

26 Stein DJ, Wessels C, Zungu-Dirwayi N, Berk M, Wilson Z. Value and Effectiveness of Consumer Advocacy groups: a survey of the anxiety disorders support group in South Africa. *Depression and Anxiety*, 2001; **13:** 105–107.

27 Temple SV. The advocacy movement in gynecologic oncology. *Seminars in Oncology Nursing*, 2002; **18:** 231–235.

28 Davis C, L S, Redman S. Evaluating the effectiveness of advocacy training for breast cancer advocates in Australia. *European Journal of Cancer Care*, 2001; **10:** 82–86.

29 Cromwell HS, Howe JW, Grady OR. A citizens’ coalition in mental health advocacy: the Maryland experience. *Hospital and Community Psychiatry*, 1988; **39:** 959–962.

30 US advocacy group moves into Europe. *European Journal of Cancer* 2000;**36:** 285.

31 Buchanan M. The role of women’s advocacy groups in breast cancer. *The Breast*, 2003; **12:** 420–423.

32 Mosconi P, Kodraliu G. Italian forum of Europa Donna: a survey of breast cancer associations. *Health Expectations*, 1999; **2:** 44–50.

33 *Social Protection and Health Care Expenditure 2001: National Research and Development Centre for Welfare and Health*, Finland: National Research & Development Centre for Welfare and Health, 2003.

34 *Social Protection and Health Care Expenditure 2002: National Research and Development Centre for Welfare and Health*, Finland: National Research & Development Center for Welfare and Health, 2004.

35 Toiviainen HK, Vuorenkoski L, Hemminki E. *Survey on Finnish Patient Organisations Shows Economic and Other Interactions with Drug Industry*. Krakow, Poland: Health Technology Assessment International, 30 May–2 June, 2004.

36 Brown P, Zavestoski S. Social movements in health: an introduction. *Sociology of Health and Illness*, 2004; **26:** 679–694.

37 Hogg C, Williamson C. Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees *Health Expectations*, 2001; **4:** 2–9.

38 Coulter A. Involving patients: representation or representativeness? *Health Expectations*, 2002; **5:** 1.

39 HAI-report. *Does the European Patients*’ Forum Represent Patient or Industry Interests? A Case Study in the Need for Mandatory Financial Disclosure. Amsterdam, Netherlands: Health Action International-Europe, 2005.

40 *The Influence of the Pharmaceutical Industry*. London: House of Commons, Health Committee, 2005.

41 Wilson J. Acknowledging the expertise of patients and their organisations. *BMJ*, 1999; **319:** 771–774.