Characterization of support groups and patient associations for individuals with rheumatologic disease in Brazil

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ABSTRACT

Objective: To analyze organizational characteristics of support groups that represent rheumatic patients in the Brazilian states. **Methods:** Initially a mapping of the desired universe was made. Contact was attempted with all organizations and they were asked to answer a structuralized electronic questionnaire with the purpose of understanding the profile of these organizations (developed initiatives, legal aspects, difficulties, strong points, among others). **Results:** 45 organizations were identified. They predominate in the south and southeastern regions of the country. Of the total, 30% have a website and 50% presented difficulties to establish contact with. Of the 12 organizations that answered to the questionnaire, 5 had closed, one is on a construction phase, and the remaining was not possible to establish contact with, or did not answer the research. Of the organizations that answered the questionnaire, only one declared having an OSCIP title (Civil Social Organization of Public Interest) or a Social Organization title and only one declared being registered at the National Council of Social Assistance (CNAS). Moreover, 50% did not present a public utility title, 25% were registered in a registry office and only 1/3 declared being registered in the City Council of Social Assistance (CMAS). **Conclusions:** The studied groups present heterogeneous characteristics. Of the organizations studied, some showed to be more solid and well-structured, but others showed important intrinsic difficulties, with an incipient profile or characteristics that demonstrate little survival expectation.

Keywords: self-help groups, rheumatology, organizational policy.

INTRODUCTION

According to Guanaes & Japur,[1] support groups or patient Representative organizations are characterized by offering support so that a certain group of people can cope with situations of stress related to common crises, life transitions, difficulties inherent to a specific problem or a specific disease. Thus, in general, these groups are directed at individuals with similar problems, willing to share their personal experiences, in which a cohesion and support process develops.

Researchers have demonstrated satisfactory results with the implementation of support groups in several conditions of health impact, such as Alzheimer's disease and its impact on the patient and the family;[2] acquired immunodeficiency syndrome;[3] cancer;[4] victims of sexual abuse by relatives;[5] chronic pain;[6] among others.

Among the positive results reported by the participants of support groups are: improvement of social resources, better level of knowledge on the questions discussed by the group, better capacity to face life situations, improvement in self-confidence, decrease in fear and ambiguity, emotional relief and decrease of the feeling of hopelessness.[7]

Such organizations are capable of reducing social isolation, increasing and disseminating information, promoting quality

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of life, enabling their participants to improve their coping strategies and solving problems, in addition to advocating for social changes and fighting for specific rights.[7]

In spite of the broad social benefit, it is necessary that these organizations always seek their improvement, enhancing their actions conscientiously, aiming at the improvement of the efficacy and effectiveness of the initiatives developed by them.[8]

Monteiro[8] points out that each group constructs its own philosophy and its own program of help. This fact results in a wide variety of groups, regarding the organizational structure and the program contents.

Schopler & Galinsky[7] emphasize the limited attention that has been given to a systematic assessment of the processes and the results conducted by each group.

Support groups and patients' associations, in most cases, fit into a profile of third-sector entities, which are non-profit, autonomous organizations, that is, non-governmental organizations, directed at meeting the needs of the population, complementing the action of the Government.[9]

The success that third-sector entities have been obtaining in the last years in the social area has increased the demand for this type of service. Thus, it became necessary for these organizations to seek new and more effective strategies to make the progress of their missions more tangible and, therefore, necessitating organizational capacity.

Many organizations, however, aim at creating new programs and keeping administrative costs low, dedicating little attention to the construction of an organizational capacity aimed at obtaining their goals effectively and efficiently.[10]

It is usual to find non-governmental entities that fight for noble causes – with dedication and persistence – whereas, however, presenting deficiencies in their planning, with few indicators of results and with a poorly-defined organizational and operational structure.[10]

Thus, the present study proposed to carry out an investigation with the objective of understanding the current scenario of patient representative entities in the area of Rheumatology in Brazil, so that a strategic planning can be conceived for the future of these organizations.

MATERIAL AND METHODS

Identification of the studied universe

To research the universe of entities that represent rheumatology patients around Brazil, the following strategies were employed: [1] Analysis in the site of the Brazilian Society of Rheumatology (SBR); [2] Analysis in the sites of each one of the Regional Societies of Rheumatology; [3] Personal contact with Group of Arthritic Patients of São Paulo (GRUPASP); [4] Contact by telephone with the National Association of Arthritic Patients (ANAPAR); [5] Google research, using the following search tools: main rheumatic diseases described by SBR and the following words: "support groups" or "patient association".

Questionnaire for research

The questionnaire (Appendix) was developed by the author of the study in partnership with the Interdepartmental Group of Health Economics (GRIDES), based on literature studies and three in-depth interviews – carried out with managers of third-sector entities that represent chronic patients.[11,12,13,14] The digital version of the questionnaire was sent by electronic mail to all associations that had an e-mail available for contact. When the entity did not have an e-mail address, the strategy was to establish contact by telephone. Additionally, in many cases, it was necessary to establish contact with the operator of each state telephone company (102) – in an attempt to obtain the telephone number from the address or name of the person in charge of the organization – information available in the general registration obtained from the data survey on the studied universe (topic 1 of *Material and Methods: "Identification of the studied universe"*).

RESULTS

Based on the data survey, 45 entities were identified throughout the country, which presented the configuration of patient representative organizations in the area of rheumatology.

Of these 45 organizations, less than 30% had their own website and approximately 50% had contacts that were difficult to have access to, characterized by non-existing e-mail address associated to a telephone number that did not correspond to the list available in the internet [1] or telephone number that went unanswered for three consecutive days on working days during business hours [2]. In both situations [1 and 2] contact was established with state telephone company operator (102) in an attempt to obtain the correct telephone number of the organizations.

Regarding the location of these 45 entities, the following data were observed: 23 entities (55%) were located in the southeast region of Brazil and 15 of them (65%) are located in the state of Sao Paulo. The south region of the country comes second, with 8 organizations (19%). After that come the Midwest and the Northeast regions, which have 5 entities

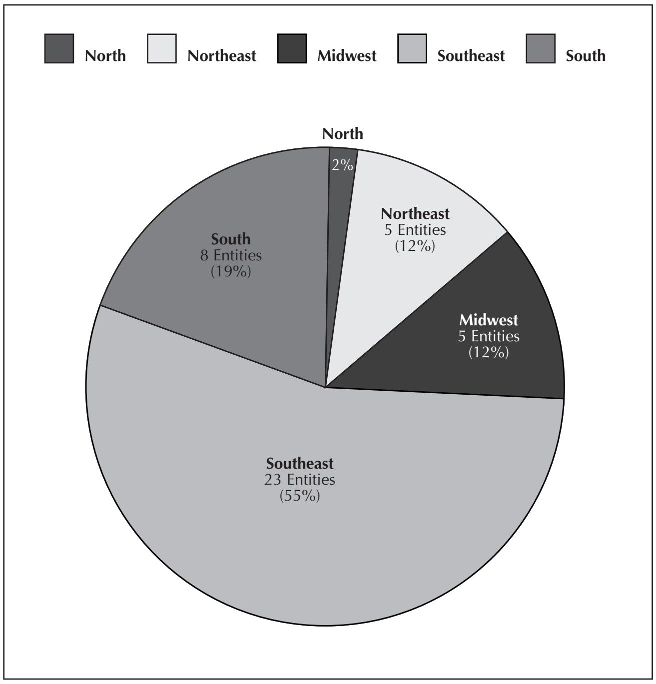
(12%). The North region comes last, with only 1 entity (2%) located in the state of Amazonas. It was not possible to locate the city/town/state of 3 mapped associations (Figure 1).

The states with the highest concentrations of entities are: São Paulo with 15 (33%), Paraná with 5 (11%), Rio de Janeiro with 4 (9%) and Distrito Federal with 3 (7%). As shown in the chart, the southeast and south regions concentrate approximately 75% of the entities.

Of the 45 mapped entities, only 12 (27%) answered the questionnaire. Of the remaining 33, five were no longer active, one was being constructed (according to the person in charge) and 27 of them were unreachable or did not respond.

It is noteworthy that the personal data obtained from the associations that answered the questionnaire were kept safe, for ethical reasons.

Based on the data obtained from the 12 entities that answered the electronic questionnaire, it was observed that only 3 (25%) have been consolidated for more than 10 years, 3 (25%) are in the process of being consolidated between 1 and 2 years and 6 (50%) between 2 and 10 years.



DISCUSSION

According to Lock (1986),[15] there is evidence that support groups appeared soon after the Second World War. The first records, however, date from the end of 1930s in the XX century, with the onset of the British Diabetic Association and the Alcoholic Anonymous.[16] According to the author, the patient associations appeared due to the shortage of resources for public health, due to increase in chronic diseases and the tendency of the community to participate in the health sector. Lock considers, however, that the great support for the development of entities came from the need of specific groups that were submitted to social isolation or stigmatization.

Throughout the last decades, the patient organizations have appeared in different parts of the world – Europe, North America and Latin America – as new collective actors, with a central role in the transformation of the health field.[17]

In the USA, the third-sector philanthropic associations have a well-established history of structuring and management. In Brazil and other countries of Latin America, these organizations started to show their strength only in the 1960s and 1970s, supported by different international agencies and are relatively unconsolidated. The difference is characterized by the strong North-American culture of associativism and volunteer work.[18]

In the present study, it was possible to observe some management difficulties in the entities that give support to rheumatic patients. Only 30% of the mapped organizations had a website. It was difficult to achieve contact by e-mail or telephone in 50% of the researched institutions. These data are indicative of the problems of communication with the target-public. At least five organizations had terminated their activities, which could be verified by contact with old members, who listed the managerial difficulties and/or lack of leadership as the main reasons for the termination of activities. These data are in agreement with the statements by McKinsey,[10] that these institutions very often have deficiencies in their planning, with a poorly-defined organizational and operational structure. The role of a leader as a vital part for good organizational function is also broadly discussed in the literature. Azevedo[19] affirms that the existence of a leader is essential for facing processual difficulties, including aspects related to the organization of assistance, its humanization and the search for higher levels of institutional responsibility with the results.

The analysis of the answered questionnaires shows that entities number 1, 5 and 9 presented a more solid organizational structure, presenting a larger number of employees, higher income or titles, such as Public Utility, OSCIP, OS or registration at the Social Assistance Councils. These are important markers for economic and procedural sustainability of third-sector entities.[17]

Most of the organizations studied depend on the work of volunteers, which can represent a structural problem due to the seasonality and lack of reliability of volunteer work. Among the organizational problems more often described by the managers of rheumatology institutions, obtaining funds is the most important one, followed by acquiring their own facility or one that would be adequate to their needs.

Figure 1 shows that most of the associations for rheumatology patients are in the southeast region of the country (55%). These data are in agreement with those obtained by Castro,[16] of 44% of the third-sector associations in the health area concentrated in the southeast region, with 21% in São Paulo and 13% in Minas Gerais. Castro also points out that the third-sector associations in the health area are relatively new and were created mostly in the 1990s and that the group of these entities is formed by thousands of small organizations, with a minority holding most employees in the sector.

According to Valero and Veiga (2007)[17] the promotion of de coalitions between associations – as it occurs in the European Union – constitutes one of the most effective ways to amplify the visibility and the capacity of patient associations whereas political actors.

Initiatives such as the one by GRUPARJ (Grupo de Pacientes Artríticos do Rio de Janeiro from Portuguese – *www.gruparj.org.br)* are worth mentioning, which develops projects of assistance for the reorganization of existing groups and helps create new groups of patients with in-person activities as well as long-distance ones, accompanying the organization for a period of two years. Strategies such as these can be important for the organizations that have the studied profile to consolidate and remain stable, having higher possibilities of survival and improving the results.

The data survey of the present study also suggest the need to identify and maintain the leaderships in the sector, in addition to actions aimed at improving the managerial resources of those in charge of the administrative structure of such entities, as well as researches capable of monitoring the work developed by them.

Table 1 – Results from the domain 1 of questionnaire: "General and legal questions"

Nº	How long have the activities been developed at the organization?	Is there a statute registered at a registry office?	How long has the statute been registered in a registry office?	Is the organization registered at the Conselho Municipal de Assistência Social(CMAS)?	Is the organization registered at the Conselho Nacional de Assistência Social (CNAS)?	Does it have a OSCIP (Organização Social Civil de Interesse Público) title?	Does it have an OS (Organização Social) title?	Public utility titles	Income
1	More than 10 year	Yes	20 years	Yes	Yes	No	No	Municipal State National	R$ 100.000,00 to 499.999,00
2	More than 10 year	Yes	17 years	No	No	No	No	Don't have it	Up to R$ 9.999,00
3	More than 10 year	Yes	17 years	No	No	No	No	Don't have it	R$ 20.000,00 to 49.999,00
4	2 - 10 years	Yes	6 years	No	No	No	No	Municipal State	R$ 20.000,00 to 49.999,00
5	2 - 10 years	Yes	9 years	No	No	Yes	No	Municipal National	R$ 100.000,00 to 499.999,00
6	2 - 10 years	No	Don't have	No	No	No	No	Don't have it	Up to R$ 9.999,00
7	2 - 10 years	Yes	3 years	No	No	No	No	Don't have it	R$ 20.000,00 to 49.999,00
8	2 - 10 years	Yes	3 years	Yes	No	No	No	Municipal	R$ 10.000,00 to 19.999,00
9	2 - 10 years	Yes	8 years	Yes	No	No	Yes	Municipal State	R$ 100.000,00 to 499.999,00
10	1 - 2 years	No	Don't have	No	No	No	No	Don't have it	R$ 20.000,00 to 49.999,00
11	1 - 2 years	Yes	1 year	No	No	No	No	Municipal	Up to R$ 9.999,00
12	1 - 2 years	No	Don't have	No	No	No	No	Don't have it	Up to R$ 9.999,00

Table 2 – Results of domain 2 of the "Organizational structure" questionnaire:

Nº	Is there an Organogram of the Organization?	How many professionals work at the organization?	How many professionals work by CLT rules?	Are there volunteer workers?	How many volunteers work at the organization?	What resources are in the name of the organization?	What is the situation of the organization facility?	Income
1	No	11 - 30	4	Yes	15	Telephone, printer, computer, secretary or receptionist, e-mail account	Rented facility and consultation rooms let for free	R$ 100.000,00 to 499.999,00
2	No	1 - 10	0	Yes	5	E-mail account	Don't have a physical HQ	Up to R$ 9.999,00
3	No	1 - 10	1	Yes	6	Telephone, printer, computer, secretary or receptionist	Rented	R$ 20.000,00 to 49.999,00
4	Yes	1 - 10	0	Yes	5	Telephone, printer, computer, e-mail account	Rented	R$ 20.000,00 to 49.999,00
5	No	11 - 30	0	Yes	All	Telephone, printer, computer, e-mail account	Rented	R$ 100.000,00 to 499.999,00
6	No	1 - 10	0	Yes	4	None of these resources	Don't have a physical HQ	Up to R$ 9.999,00
7	Yes	1 - 10	1	No	0	Telephone, secretary or receptionist, e-mail account	Rented	R$ 20.000,00 to 49.999,00
8	Yes	1 - 10	0	Yes	3	E-mail account	Let for free	R$ 10.000,00 to 19.999,00
9	Yes	11 - 30	3	Yes	20	Telephone, printer, computer, secretary or receptionist, e-mail account	Faciliy belongs to the organization	R$ 100.000,00 to 499.999,00
10	Yes	1 - 10	0	Yes	6	Secretary or receptionist, e-mail account	Let for free	R$ 20.000,00 to 49.999,00
11	Yes	1 - 10	0	Yes	15 to 20	Telephone, printer, computer	Don't have a physical HQ	Up to R$ 9.999,00
12	Yes	1 - 10	0	Yes	5	None of these resources	Don't have a physical HQ	Up to R$ 9.999,00

Table 3 – Results of domain 3: “General and communication questions”

Nº	Organization’s main difficulties	Have you gone through a strategic planning process for the organization?	How many times have you gone through a strategic planning process?	Do you have any type of newsletter, booklet or folder?	What kind of newsletter do you have?
1	1- Obtaining resources 2- Organization’s own real estate	No	0	Yes	Quarterly report (through donations)
2	1- Physical space for para meetings and consultations. 2- Personnel involved with availability for volunteer work. 3 - Money.	Yes	Many times	Yes	Occasional booklets and folders
3	1- Social contributions 2- Lack of HQ 3- Sustainability.	No	We make our own planning	No	Don't have one.
4	1- Lack of a large HQ building to develop other activities 2- Lack of resources to develop support and assistential services for the associates (food, clothes, medications, Communication: folder, release, newsletter). 3- Not enough volunteers.	Yes	Every year.	No	We have just launched our Blog in the Internet, but we do not have the funds to make a monthly newsletter for our associates (more than 400).
5	1- Obtaining funding. 2- Lack of physical space in the current address to offer all the services. 3- Dissemination of our services to patients from other hospitals.	Yes	Every year.	Yes	Newsletter and folders
6	1- Give the patients a higher degree of participation. 2- External activities 3- Dissemination of Meetings	Yes	Every year	No	Don't have any.
7	1- Sustainability (uncertain partnerships and undefined values). 2- HQ rent and expenses 3- Social contributions	No	We make our own planning	No	We are currently working on our first newsletter and intend to release it this month.
8	1- Obtaining donations. 2- Volunteer workers. 3- Obtaining medications.	Yes	2	Yes	Folder Newsletter
9	1- Sources of funding. 2- Maintaining the supply of medication distribution. 3- Committed supporting partners.	Yes	Every year	Yes	Booklets and online information
10	1- Financial sources. 2- Human resources. 3- People’s commitment.	Yes	1	Yes	Journal
11	1- Physical space. 2- Supporters.	No	1	Yes	Booklets with information on the disease, site, Orkut
12	1- Fund raising by associates. 2- Recognition of the syndrome by the government, to able to receive resources. 3- Specialization and qualification of professionals in the area.	No	0	No	Through our Blogs

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