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Two-front individualization: The challenges of local patient organizations

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ABSTRACT

Patient organizations such as those in Sweden face individualization processes on two fronts, both in their own voluntary sector and in the healthcare sector. The aim of this study is to investigate how the patient organizations are handling the two-front individualization process internally in their organizations, as well as externally towards a more patient-centred healthcare system. With more diverse stakeholders and individual patients given increased influence, we would expect a corresponding adjustment in the strategies of the patient organizations. The article's focus is on the organizations' representative role, and theories on advocacy strategies are used to identify the nature of the patient organizations' advocacy work. To find out how adjustments are made, 17 semi-structured interviews were conducted with representatives from local branches of three large Swedish patient organizations. The interviews show a low tendency to adjust as a response to this two-front individualization and illustrate a paralyzed rather than modified behaviour in these organizations. Individualization being a global trend, we believe these results are of interest to scholars of collective participation in all parts of the world.

KEYWORDS

Individualization; patient organizations; voluntary organizations; participation; organizational change; healthcare reform

Introduction

Individualization in our society is a well-noted phenomenon, with continuous reports on how the individual is increasingly acting autonomously as opposed to according to a group logic (Avineri & de-Shalit, 1992; Bauman, 2001; Ferge, 1997). Individualization may be viewed as an umbrella concept that includes change processes in all sectors of society: the state, market, civil society, and the family sphere. These processes include developments as diverse as professionalization of civil society organizations (CSOs), and rationalization and pragmatism at the individual and organizational levels (Le Grand, 1997; Maier, Meyer, & Steinbereithner, 2016). Another development closely linked to individualization is the *marketization* of public welfare services, with its emphasis on individual choices and diversification of both services and providers.

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In this article, we study the intersection of two types of individualization. CSOs often constitute a bridge between sectors, ending up in an interesting position, where they meet individualization processes both in the voluntary sector (internal individualization) and in the sector they are bridging (external individualization), in this case the healthcare sector. As an example of this, we focus on two concrete individualization processes facing patient organizations (POs) in Sweden. The first is the individualization expressed as marketization of the Swedish healthcare system, with freedom of establishment for providers and a general consumerist presence that emphasizes traits of individualization such as choice, patient rights, and increased patient participation (Blomqvist, 2004). Second are the challenges that the membership-based civil society meet as the idea of large groups gathering around a common need (i.e., the classical social movements) are becoming weaker (Hustinx & Lammertyn, 2003).

Interest organizations such as POs have traditionally had a strong impact on policy making in Sweden and in other Scandinavian countries. They have been important in anchoring policy decisions within certain citizen groups. This corporatist system has been described as an exchange between interest groups and policy makers, based on the idea that one part controls something desired by the other (Öberg et al., 2011). The corporatist tradition, however, developed in a time when all healthcare was in principle provided publicly and there were no opportunities to choose among providers. A shift towards a more individualistic health system is now taking place, in which patients increasingly are addressed as individuals with unique needs rather than as collectives gathered around one diagnosis, and healthcare is provided by several actors that compete under market-like conditions. We would expect POs to respond to the fundamental system changes in Swedish healthcare, which include an increase in the types of providers and to patients given increased individual opportunities to influence healthcare. For instance, organizations could develop their role as consumer guides or contribute to public procurements with their expert knowledge (Feltenius & Wide, 2015). Other changes observed in the voluntary sector are a greater professionalization, by enhancing organizations' marketing strategies, and a relaxation of the relationship to their members or even a dissolution of traditional membership structures (Ahrne & Papakostas, 2002; Hustinx & Lammertyn, 2003).

This article investigates how the POs, specifically in their role as patient representatives in the policy making process, respond to the challenges of both an internal and an external individualization process. The underlying question in this article is how the archetypal Swedish POs act in this changing environment. Which paths, if any, are chosen to adapt to their new setting? We focus on the adaptation at the local and regional levels in organizations that were established in the corporatist age of the mid-twentieth century, and the results are applicable to other types of CSOs that find themselves in similar positions. The working conditions for the local and regional branches of the POs (here jointly referred to as 'local') are fundamentally different from those at the national level, which are more professionalized. Yet they serve an essential legitimizing, grassroots function for the POs as well as a democratic function in the healthcare system, which is managed by 21 democratically elected regional authorities. The self-governing Swedish regions are responsible for funding and providing healthcare. Decisions about patient fees, staffing levels, prioritized treatments, medications, and other issues are taken at this level. It is therefore important to study the POs' local and regional efforts in influencing healthcare policy.

Starting with a description of the kind of organizational environment Swedish POs operate in, today and historically, we continue with an overview of the literature of the two parallel individualization processes: market reforms within healthcare, and the individualization changes in civil society in general, and more specifically the interest organization and POs.

Swedish POs

POs range from larger, stable organizations to more network-like ones. There are those run by people suffering from a condition and those run by the next of kin. Furthermore, there are those targeting a specified diagnosis as well as broader disease groups. Yet, the Swedish POs still have several common traits. Many of the larger POs were founded during the twentieth century. These organizations, often referred to as *popular movements*, have since been a consistent voice in Swedish healthcare politics. In these organizations, like most of Swedish interest groups from this era, the strategy has been to function as the representative of their members' interests, rather than pursuing activism to influence policy makers (Grassman & Svedberg, 1996; Rothstein, 2001).

Swedish POs have a *supportive role*, a *service-providing role* and a *representative role* (Swedish Agency for Health and Care Services Analysis [SAHCSA], 2015). These roles have different counterparts. The supportive role is directed towards the members, for instance as a forum for exchanging experiences or arranging activities such as lectures. The service-providing role is either directed towards only members, or to all patients in need of a service. The representative role, however, targets decision makers, healthcare providers as well as the public (SACHSA, 2015). The activities linked to this role range from trying to influence a specific issue to more general representation. The representative role is the one that historically has been strong in comparison to other countries (Werkö Söderholm, 2008).

The typical Swedish PO has a national body and local and regional branches. Members join the local branches, and these representatives join into a regional board, coordinating interest politics at the sub-national level. The regional boards operate closely to the regional authorities governing and providing healthcare. The national branch of the organization, usually based in Stockholm, with employed and professionalized staff as well as an elected board, provides support and direction for the local/regional branches, performs lobbying towards the national government and run larger campaigns. The local branches, which are focused here, are traditionally rooted in the supportive role. However, it is often established in the statutes, and therefore expected, that they engage in interest politics at the local level, thus also carrying out their representative role. Local government often offer corporatist structures to enable participation from the local branches. Adding the aspect of Swedish healthcare being decentralized and provided in the regions, the representative role becomes even more important at local and regional levels.

Previous studies on POs, specifically in their advocacy role, indicate a problematic position as an invited participant in policy making, but still holding a very dependent position, guarding and maintaining smooth relationships with actors such as pharmaceutical companies, medical professionals and politicians (Van de Bovenkamp, Trappenburg, & Grit, 2010). The Swedish POs seem less dependent on pharmaceutical interests (SACHSA,

2015), but the inherently dependent position of the patient in relation to healthcare professionals and decision makers, of course, remain making the patient organization structurally weak in relation to other interest organizations. Nevertheless, they are and have been continually invited to participate in policy dialogues in Sweden.

Individualization Processes

Healthcare

As a reaction to a strong tradition of paternalism, professionalism and bureaucracy within healthcare, ideas about patient-centred care have recently permeated healthcare, from reimbursement systems to the development of individual treatment plans.

In policy and practice, patient centeredness is expressed in various ways. The basic structure of the healthcare system is adapting to the new focus on the individual patients and their increased potential to influence services. At the structural level, these changes have manifested themselves mainly in the introduction of market mechanisms to induce competition to increase opportunities of choice for patients and to make services more diverse. Whereas in other countries, such as for example the U.K., patient involvement may be more directed towards participation and developing healthcare services, patient participation development in Sweden today is more related to the patient as a consumer, with the right to choose and influence service provision as a consumer (Tritter, Koivusalo, Ollila, & Dorfman, 2010). However, the effectiveness of patient choice as a steering mechanism and mechanism for influence has been questioned. First, it has been difficult to create functioning markets in rural areas; second, these reforms have not been initiated by patients themselves; and third, the exit mechanism is thwarted by the desire for continuity, which is especially important within healthcare (Fredriksson, 2013; Tritter et al., 2010; Winblad & Isaksson, 2013).

In sum, these changes in the healthcare system imply two essential institutional developments relevant for the POs. First, they promote and encourage a new, perhaps competing, way of being involved compared to the traditional method of collective mobilizing. As more emphasis is put on individual choice as the main channel for patient influence, less attention is possibly given to traditional collective participation. Second, due to the opening of the market to private providers, healthcare provision has become diversified and perhaps not as easily influenced compared to when healthcare was provided only by the public sector. Power has dispersed across numerous actors: politicians, public healthcare providers, private healthcare providers, and increasingly towards the individual patient.

The Voluntary Sector

Other examples of individualization can be found within the voluntary sector itself. These changes are more difficult to pinpoint, as they cannot be attributed to specific policy reforms. For instance, the idea of a group identity has become gradually weaker. Hustinx and Lammertyn (2003) describe in detail the differences between collective, traditional volunteering, and modern, individualized (or reflexive) volunteering. For example, modern life is disruptive and lacks the continuity that is required for traditional

long-term volunteering; it demands that volunteering now be flexible. Furthermore, the modern volunteer seems to be more pragmatic than idea-driven. This pragmatism leads the volunteer to choose activities mainly from personal interest or benefits, rather than based on the collective goal of an organization. What's more, the professionalization of civil society has created a focus on accomplishment and effectiveness rather than the good-will of amateurs (Hustinx & Lammertyn, 2003).

Besides pragmatism, an important aspect of individualist volunteering is rationalization, which describes an increased systematization and structure within the organization, for increased efficiency (Papakostas, 2011). The demand for volunteer labour has decreased due to new ways of communicating to the masses, leaving little room for the traditional, collective group identity among members (Skocpol, 2003; Tranvik, 2004).

Two seemingly contradictory trends can be noted in the literature. On the one hand a centralization process, connected to the increasing passivity of members and a general weakening of membership-based organizations following the reduced need for volunteer labour (Ahrne & Papakostas, 2002). On the other hand, civic engagement is redirected to smaller, local forms of organizations with a narrow focus. These initiatives are typically not part of the traditional federal organization structures but rather are informal, often short-term, and project-based (Papakostas, 2011; Skocpol, 2003; Tranvik & Selle, 2007). Both trends illustrate how the space for collective engagement is decreasing in formal organizations. The changes in civic engagement occurring today requires structural adaptation to new forms of volunteering for CSO survival (Hustinx & Lammertyn, 2003).

As we have seen, POs are operating in a dynamic environment where individualization is at play both internally, within the organization and the voluntary sector, and externally in their advocacy counterpart, the healthcare system. The main interest of this article is possible adaptations by the local branches regarding *influence* on healthcare, i.e., when carrying out their representative role, whereby the focus will be on the advocacy strategies used by the POs. In what follows, a short review of the literature on a common categorization of interest group strategies leads to a table that covers possible strategies of influence as well as other activities of the PO.

Theoretical Framework

Two Ideal Types of Advocacy Groups

A common division in the literature on advocacy strategies is that between insider organizations and outsider organizations. An organization with insider strategies mainly uses contacts with decision makers to influence policy. The outsider organization lacks this opportunity and thus must fight from the outside to pose external pressures on policy makers (Grant, 1978; Page, 1999).

Insider strategies can be divided into two main methods: corporatism and lobbyism. The traditional way for established Swedish advocacy groups to interact with decision makers is through institutionalized arrangements such as advisory boards and by acting as consultative bodies, i.e., through corporatist structures. Another way for interest groups to approach politicians and decision makers is by simply contacting them when needed, either through letters, meetings, or phone calls. These interactions outside of the corporatist structures can be defined as lobbyism (Munk Christiansen & Rommetvedt,

1999). Whereas corporatism often requires an invitation from the decision makers, the interest group itself initiates lobbyism. Lobbyism offers a more flexible, less demanding system, largely because it does not require long-term commitment (Munk Christiansen & Rommetvedt, 1999).

Those organizations that do not have the necessary connections and resources to carry out insider interaction may instead turn towards the public and draw attention to the issue. Media and mobilization strategies are more common when organizations try to attract members in order to appear active and efficient (Beyers, Eising, & Maloney, 2008). Focus on service and social activities among POs may be used as an incentive for potential members to join the organization and thus become a strategy for staying mobilized.

Changing Environment, Changing Strategies?

The traditional corporatist system of Swedish policy making has successively declined in power. The extent of the decline is disputed, but many agree that interest group involvement in policy-making is no longer as desired by policy makers compared to the 1970s (Munk Christiansen, 2017; Öberg, 2015). One reason for this can be linked to the individualization processes within civil society, as the fragmentation and pluralization of participation and engagement inevitably leads to weaker interest groups. As described by Munk Christiansen (2017), the corporatist system presupposes that interest groups are strong. If not, policy makers may not believe they benefit from the exchange. Öberg (2015) confirms this, and concludes that in this pluralized political landscape, media attention and participation in open debates become increasingly important. Apart from the individualization processes within civil society, the similar process within the healthcare sector affects the behaviours of POs. The individualization, mainly expressed here as marketization, has, too, created a fragmented healthcare sector, where power relations have changed from being centralized to being scattered across different healthcare providers and individual patients. In sum, insider strategies require a stability both regarding advocacy counterparts in the healthcare system, as well as a stability in membership and engagement within the civil society sector. Outsider strategies, however, do not require such stability. Based on previous research in this field, along with our knowledge on individualization within civil society and in the healthcare sector (mainly in reference to market reforms), we expect that insider strategies, connected to the corporatist system, will be weaker among today's POs. Thus, outsider strategies more adjusted to the new pluralistic civil society will be the main choice of the organizations to effectively carry out their representative role.

Speaking against these adaptations is organizational inertia. In the Scandinavian context, these types of organizations originating from the popular movement tradition have difficulties breaking away from what have been seen as the ideal form of a CSO for a long time (Åberg, 2015). This inertia, though, is likely due not only to *unwillingness* to change. *Inability* to change is another strong factor, which can be explained by blindness of the need for change, formal obstacles like organizational structures, and perhaps most importantly a lack of resources (Ahrne & Papakostas, 2002).

To enable a deeper understanding of what activities may illustrate insider and outsider strategies respectively in the case of POs, a table was created inspired by a similar compilation made by Binderkrantz (2005). Her main division was that between *direct* and

indirect strategies, where 'direct' can be equated with insider strategies and 'indirect' with outsider strategies (Binderkrantz, 2005). Our version was adjusted to fit POs and has been extended to include also its supportive and service-providing role (SACHSA, 2015). In the original table, there were only two kinds of insider strategies: administrative and parliamentary. In our table, direct contact with healthcare providers was added as a way of interacting with decision makers. Table 1 will be used as a navigational instrument when analysing the interviews with members of local POs. Our ambition is not to specifically check the boxes in the table, but rather to identify a coherent logic in the activities of the studied organizations. With a base in previous literature, it creates an overview of what POs *can* do, thereby helping us to discover what they do and what they choose *not* to do.

Methodological Considerations

To develop an understanding of how the POs are operating and why, 17 interviews were conducted with representatives of local and regional branches of Swedish POs. Interviews were semi-structured, with questions covering concrete routines such as organizational structures, activities, and advocacy strategies as well as reflections on the purpose of the activities and changes in the policy environment.

Three traditional POs formed in the middle of the twentieth century were chosen, based on the case selection logic of the *typical case*. With their long histories and large membership bases, they represent a large group of patients, and they are organizations that are and have been *typical* for Swedish civil society. The implications of the results are thus valid for many Swedish patients as well as for many Swedish CSO:s, and likely for other CSO:s established during this period. The limitation of this selection is, of course, that we cannot provide a complete picture of the POs in Sweden. We did not cover recent small-scale initiatives that were developed in the more individualized environment. Furthermore, because we are interested in organizational change and adaptation, we further limited the study to organizations that have been active over a longer period.

The chosen POs were the Swedish Heart and Lung Association (SHLA) (founded in 1939), the Swedish Diabetes Association (SDA) (founded in 1943), and the Swedish Psoriasis Association (SPA) (founded in 1963). All three organizations were formed and developed during the corporatist system that dominated the twentieth century in Sweden, and they have local representation in all Swedish regions. None of these organizations have employed staff at the local or regional levels, and work is thus voluntary. The SHLA is one of the largest POs in Sweden, with 38,000 members as of 2016. SDA is also large, with around 22,000 members. SPA is somewhat smaller, with about 15,000 members. One may argue that there are substantial differences among these three organizations due to the different nature of the conditions, both in terms of the number of possible members and the public interest. Regarding the purpose of this study, however, which is solely to understand how organizations relate to a changing environment, such issues are of secondary importance. Rather, their differences are welcome as a way of broadening our understanding of the responses of large and stable organizations. The basic organizational structures of the three organizations are nonetheless largely similar and meet the criteria of the typical case in regard to the general population of Swedish POs.

Table 1. Patient associations' activities, developed from Binderkrantz (2005) and the SACHSA (2015).

Representative role: insider strategies			Representative role: outsider strategies		Supportive role		Service-providing role	
Administrative	Healthcare	Parliamentary	Media	Mobilization	Information	Social support	Publicly financed	Private/informal
Participate in public committees	Participate in patient and expert groups within healthcare services	Contact regional committees	Contact journalists	Arrange meetings for the public	Provide guidance in healthcare system	Be a social platform through activities	Provide treatments through patient choice system	Self-financed treatments/ rehabilitation
Contact public servants	Contact healthcare professionals	Contact politicians	Write columns in local newspapers	Conduct petitions	Inform about new research	Arrange study circles	Provide treatments through public procurement	Educate in self-care
Respond to requests for comments	Contact hospital and clinical boards	Contact party organizations	Issue press releases	Organize demonstrations, civil disobedience	Inform through lectures	Arrange camps		

We conducted 17 interviews in the local branches of the three organizations in three large regions in Sweden. The ambition was to conduct interviews with two representatives from the same local branch (preferably the largest) in each region, with one being the head of either or both the local and regional board and the other being an ordinary member of the local board, although some exceptions were made (see Table 2 for more information on the respondents). Interviews were performed between November 2016 and March 2017, mainly in physical meetings but also through telephone conversations, and lasted 40–90 min. All interviews were recorded and transcribed. The transcripts were broken down into meaning units, which were categorized into nine categories based on the table above (Table 1). Additionally, three categories were constructed inductively. These helped in discerning general themes that seemed important for the local and regional board members.

Findings

This section starts with the local POs' experiences of individualization reforms in healthcare, sparked by marketization, and general individualization processes within civil society at large. Thereafter, we move to identifying signs of insider/outsider strategies used by the organizations.

Individualization and Market Reforms in the Healthcare System

The three regions studied here have different proportions of diversified services through private providers and of individualization through patient choice. The interviews show that local board members in the region with the lowest share of private providers are not as informed about patient choice reforms and marketization as the others. Nevertheless, when asked specifically on how these reforms affect the PO's work, most of the local board members in the three organizations had nothing to say and had not reflected on the matter. They had not heard any complaints from members or experienced problems themselves.

Table 2. List of respondents.

Respondent code	Organization	Local Branch number	Position in local board	Position in regional board
R1	PSA	1	Chair	Chair
R2	PSA	2	Chair	Chair
R3	PSA	2	Board member	
R4	PSA	3	Chair	Alternate
R5	PSA	4	Chair	
R6	SDA	5	Chair	
R7	SDA	5	Board member	Board member
R8	SDA	6	Chair	Chair
R9	SDA	6	Board member	Board member
R10	SDA	7	Chair	Chair
R11	SDA	8	Chair	Board member
R12	SHLA	9	Board member	Chair
R13	SHLA	9	Chair	
R14	SHLA	10	Chair	Chair
R15	SHLA	10	Former Chair	
R16	SHLA	11	Chair	Chair
R17	SHLA	12	2nd Chair	

According to the local board members, patient choice reforms and privatization had not affected the role and activities of the POs per se, albeit with some exceptions. One respondent acknowledged that it is vital for the local organizations to take part when the region constructs new procurements contracts for healthcare providers. Another, more common effect that many local board members referred to is the mushrooming of local health centres in the larger cities, which is a well-known effect of the patient choice system (Swedish National Audit Office, 2014). This was seen as a challenge by three respondents, as they wish to provide the local health centres with brochures, and it had become difficult to reach out to all of them. However, these board members did not describe a way to actively cope with the problem. A representative of the SPA expressed in a typical way the difficulty of keeping relationships with all the local health centres:

> Before we were so much better; we were updating the binders and had contact. Now it's more that we try to keep an eye on the skin treatment facilities instead. There are so many healthcare centres now. I do believe we had a personal connection before, with the ones working at the healthcare centres. That makes it easier. Now we need to make new connections. (R3)

The respondents went quickly from speaking of the marketization and choice reforms to the issue of centralization of healthcare services. This was a recurrent theme in most interviews, and it clearly is something the local branches are more concerned with. In practice, the problem is that people living outside the larger cities are forced to seek healthcare further from their home, even for minor treatments, which complicates their daily lives. Some respondents linked this to the marketization reforms and the free establishment for providers, but others linked centralization to financial cuts in healthcare. Nonetheless, what was important to many local board members was the effects on healthcare, and if patient choice leads to increased access to healthcare – which is true in urban areas – they would consider it a beneficial reform. Thus, their position was clearly pragmatic rather than ideological.

Marketization reforms such as patient choice only seemed to generate an active change in the organizations' behaviour when it came to setting their advocacy agenda. The way the reforms have affected their members' access to healthcare, for example by services becoming more centralized because of privatization, had on several occasions determined which issues were put on their advocacy agenda. However, the interviews did not show any signs of change in *how* their advocacy strategies are carried out. For this reason, we can conclude that the local board members have not seen a need to change the actual strategies and routines of the local organization as a response to market reforms. The market reforms seem to only affect agenda setting, not advocacy strategies.

Individualization Within Civil Society

Boards With Little Energy

All local board members described a decrease in membership numbers over time. The recruitment of new members is a constant ambition, according to the respondents, and many of their activities have recruitment as an important part goal. There is an obvious demographic issue: younger people tend not to join POs. The local board members explained this by mentioning young parents' hectic schedules and people getting

information from the Internet rather than through the organization. The interviews described a general trend that most are passive members, paying mainly for a membership newsletter and staying up to date with research and changes in healthcare policy. The lack of engagement is a problem that all local branches but one spoke of, and it reappeared throughout the interviews. The lack of members and the passivity of existing members have a negative impact on how much work can be done to influence policy, partly because these deficits weaken the organization's legitimacy and partly because resources in the board must be directed to recruiting members rather than pursuing political issues.

However, recruiting board members is even more problematic. This is naturally a consequence of the lack of engagement among existing members. All local board members reported being recruited themselves as soon as they entered the organization, and many were elected chairperson on their first meeting. The local board members described a pattern of local organizations outside of the larger cities closing or joining together to survive. In some local organizations there is no chairperson, and one local board member acts as chair of two local organizations at the same time. Nearly all local board members expressed that the boards need new energy and new people, and that the board members are often too tired to initiate new projects or new strategies. A common situation seems to be that activities and work are carried out by the chair of the board, who has built the current relationships with healthcare providers and politicians; therefore, it will be difficult to replace the chair. Summing up, we find signs of the passivity among members, associated by Ahrne and Papakostas (2002) to a centralization process, and no clear signs of project based movement, as mentioned in the literature as a sign of fragmentation of the CSO sector (e.g., Skocpol, 2003).

Members First, Politics Second

When asked about the most important role of the organization, it became clear that the local representatives see the organization first and foremost as a support for the members. Thus, they emphasize the supportive role. The purpose of the organization seems to be to make everyday life better and easier for people diagnosed with diabetes, psoriasis, or heart and lung-related diseases. This can of course be fulfilled in different ways. Faced with the question 'Which is more important, being a support for members or representing members in local politics?', local board members often replied that both are important, but continued developing their thoughts only regarding the supportive role. A representative from SHLA described that support is what members want:

> Most of the people come, really, to get information and get in touch with people that have gone through this and can tell them how to move on. (R15)

Most of the respondents expressed that an important part of the work in the board is to inform patients through lectures and other types of information, and to help them self-manage their condition. A couple of board members suggested that information also is a way to strengthen the patients in their interaction with healthcare professionals. Furthermore, the board members commonly wished for more social activities, as they saw the social aspect of joining the organization as important, yet all had experienced problems getting members to take part in them. A few of the local branches are discussing whether they are to arrange these social activities at all in the future. It became evident that the members and the board members prioritize social activities differently. Provision

of rehabilitative or preventive treatments or training was to some extent provided by the organizations, and by some seen as essential in attracting new members.

To conclude, it is important in our further analysis to remember that while political influence is the focus of this study, it is not the main focus of the local POs. Although recognized as important, political influence comes second to securing a stable membership base and keeping these members in possession of the information they need and request. However, this is not easy to do, as members often are passive and disengaged in the organization.

Insider or Outsider Strategies for Influencing Healthcare Politics?

Typically, the local organizations pursue one or two policy issues per year, often the same issues as the national organization. Additionally, local issues may be addressed. A recurring theme is access problems, because of a centralization of healthcare clinics to larger cities or the lack of specialists within primary care. Interest politics is carried out at the regional level rather than the local level. Local initiatives exist in the larger regions and are mostly a response to cutbacks in the local healthcare centres or specialist clinics.

Outsider Strategies

The strategies for influencing healthcare politics mentioned by the board members were almost without exception insider strategies. The interviews showed that using media to attract attention to issues locally is uncommon (see Table 1). Arguments against this strategy mentioned by the board members ranged from the difficulty of being published in local media to the lack of writing and argumentation skills. Occasionally a journalist may contact them if there is an issue gaining public interest, such as the shared patient medical record systems or the closing of a popular local clinic. Demonstrations and other mass mobilizing initiatives (see Table 1) are difficult to arrange, according to the respondents, and a probable explanation is the lack of enthusiastic members. Contemporary ways of mobilizing, such as through social media, are very uncommon in the local POs. Some respondents stated that they actively refrain from social media, in fear of hateful comments and false information. Others use them, but only in closed groups to inform members on social activities. This was explained in the interviews by the relatively high age of the members, and their unfamiliarity with social media. Previous research has shown that outsider strategies are more common among organizations with a wide target group, and this is probably an important reason as to why they are unusual within POs, and especially at the local level where the target group is even smaller (Binderkrantz, 2005).

Although outsider strategies are rare, many local board members stressed the importance of being visible in the community. A representative from SPA explained this:

> I really think it's important to be visible, because if you are visible you are participating. If you are visible, it's harder to neglect those people. I don't know what's more important, being visible or influencing politicians, but I do believe it's very important to be seen. And I think we should be more visible, really. (R3)

Interestingly, the citation indicates an acknowledgement of the value of visibility, but there was no indication of them acting on it. This respondent explained this with lack of

resources, visibility was simply too expensive. According to the local board members, important strategies for the organizations to be known in the local community include handing out information in public places, leaving brochures at pharmacies, putting up posters for social activities, and showing up at different forums such as International Diabetes Day. Therefore, the outsider strategies may be few and not very efficient, but the local board members reported valuing them as a part of a larger, long-term strategy. They are not, however, used as an adjustment to individualized behaviour among volunteers by lowering the threshold for engagement.

Apart from being a strategy for recruiting members, which is in line with previous research (Beyers et al., 2008; Binderkrantz, 2005), outsider strategies are rarely used for advocacy in these organizations. Some respondents indicated the importance of communicating with healthcare professionals, but this does not seem to be a consequence of the diversification of providers but rather a question of speaking to the right person which they have always sought to do. Only one respondent emphasized the importance of influencing the specifications and criteria in the procurement contracts; however, since this is done centrally in the regional administration, it cannot be seen as a way of advocating towards private providers. Furthermore, we do not see the organizations increasingly supporting individual patients in their new consumer role.

Insider Strategies

The first choice of advocacy strategy for most of the board members is to write a letter to the regional politician in charge of healthcare, but phone calls and meetings were also mentioned as common ways of communication (see Table 1). Successful contacts with politicians are clearly dependent on a personal relationship. One board member stressed the importance of being flexible and adjusting the strategies and approaches depending on the politician.

> You need to find an ear. So, it comes down to finding a couple of people in the healthcare board, someone who is interested. And then you never know if you find them among the opposition or the ones in power. So, you need to find friends on both sides. (R2)

In addition to using direct political contacts, the local branches are active in different committees and dialogue groups in their region (see Table 1). Some of them are focused on the diagnosis or medical condition, and on gathering together medical experts, public officials, and patient representatives for a common purpose, for instance for serving on a regional diabetes council. Others concentrate more on occasions for patient dialogue, such as gathering representatives from different POs and patient groups to give their views on healthcare issues, which one region calls a patient participation council. These forums function as ways of receiving information from the region and for the organizations to bring up issues. A problem that some respondents mentioned is that these meetings are too rare to be an efficient way to communicate, and that they can even function as a filter. They may be invited to participate in different forums, but many important decisions and changes are not communicated to them at all, and it is usually up to the local branches themselves to ask for information from politicians or civil servants. A representative from SHLA expressed a typical problem regarding a participation committee he is a part of:

> The regional healthcare committee … From that group, we do have a certain influence; we meet with our regional politicians there. But the information on the meeting will get to us one, maybe two days ahead, some paper about the agenda. And then after the whole program we can ask questions. It's one-way communication. It works really badly. (R15)

Furthermore, to have an impact it is important that the local organization is invited during a certain phase in the policy process, which is easily missed if meetings are held only twice a year. Nevertheless, several respondents experience these committees and dialogue groups as a good way to be seen and heard, and to receive useful information. The corporatist traditions are visible here in the way that these relationships are kept friendly and non-confrontational. The local branches value their established networks, and some board members defended 'their politicians' despite the politicians' acting contrary to the organization's wishes. Consequently, we find contradictory responses regarding the usefulness of participating in these committees among our respondents, which may indicate a transitional phase. Some respondents are starting to question the system's efficiency, while some still see opportunities with participating this way.

The interviews showed that some local organizations have a specific contact, often a recognized physician or nurse within their medical area, to whom they turn as a reference in interaction with other decision makers (see Table 1). These contacts are used to bring weight to their arguments and can also be asked to sit in during meetings with politicians or in public debates. Healthcare professionals sometimes also act as an ear to the ground, providing the local boards with policy information earlier than they would otherwise get it. Furthermore, many of the issues of interest to the local board members concern clinical processes or medical technology. Examples are the premature discharge of patients or doctors failing to provide timely diagnoses. Politicians do not control these aspects of healthcare; professionals do. The relationships with medical professionals are thus clearly important to the local branches, but not as a result of marketization.

Humble Advocates

Although the interviews showed that the studied local POs still act in line with the traditional Scandinavian corporatist structures, such structures would suggest an exchange of some kind, implying that these local organizations have resources and legitimacy desired by the decision makers, thereby making them more willing to meet some of the organizations' demands (Öberg et al., 2011). The lack of outcome that the organizations experienced from contacts with politicians suggests, however, that they do not have the weight that is demanded in these relationships. When asked about the effect that these meetings and contacts may have, most local board members – with some exceptions – said that the effect is small or non-existent. However, the board members expressed surprisingly little frustration over this. There were of course pessimistic outlooks from some of the local board members, but a larger group of board members were tolerant and understanding towards politicians, suggesting that they probably do their best in a very difficult position. They mentioned that most politicians have a positive attitude towards the organizations and listen to them. The approach from some of the local board members is that their purpose as an interest organization is not necessarily to change the policy in their favour but to provide decision makers with a better basis for their decisions. One local board member referred to the democratic process and declared that it is not up to them to stand in the way of elected politicians.

> It's the thing with democracy and how people vote – we cannot interfere with that. We can just influence by pointing out to politicians what reality looks like. And then of course we can have our own opinions. (R10)

Rather than confronting politicians and holding them accountable to problems in the health system, it seems that a long-term harmonious relationship with politicians is important for the organizations, and indications of a conflict or a struggle were rarely mentioned in the interviews. Insider strategies are clearly popular despite their weak effect.

Old Tracks

An important factor as to why these insider strategies are dominating could be the lack of engagement in the organization. Sticking to the old routines, contacting the same people or using the same methods is natural when energy is low in the local branches. Even though they are aware that politicians have small prospects for changing policy in their favour (and do not really expect them to), they continue in old tracks. Also, although the different participation committees in the regions are appreciated, they are an easy way to engage in politics. Some local board members admitted that this kind of participation basically is for showing it in the annual reports.

Most of the local board members expressed a wish to be more active with interest politics, tying the low activity to a lack of time and resources. When asked what they would do if they had more resources, all local board members discussed doing more of what they are doing now, possibly through some employed staff. No new initiatives or creative solutions came up, indicating that big changes are not really discussed. From the interviews, it became evident that the lack of engagement from members is the main reason why local branches act the way they do and refrain from acting the way they would prefer.

Towards a Challenging Future

These types of POs, like many other CSOs, are likely to face even harder times, according to the interviewed board members. There is little hope that the future will bring more engaged members in this kind of traditional organizations. When asked if something should be changed in the way the organization is operating, most local board members could not see how a change is possible. The traditional way of running a small, local organization seems to be rather undisputable. A local board member from SHLA described the lack of changes in the local organization:

> Volunteering has been the same for a long time – meetings, protocols, and so on. There are no changes. And there really is no need to change, is there? Not if we are to have this system with associational life, because this is a part of it. (R16)

When local board members were asked what they would do if they had more resources, they still spoke of insider strategies. It is not possible to decide from these interviews what would be a more fruitful way for the local POs to carry out their representative role. However, new ideas in management, online campaigning, marketing, or membership forms in general have not developed among these local organizations, despite such trends in other parts of civil society, suggesting that organizational inertia could be one explanation to their behaviour.

Conclusions

The purpose of this study was to investigate how local POs handle the two-front individualization they are facing today, both internally within the voluntary sector and externally with their counterpart, the healthcare sector. Based on literature on the implications of these individualization processes, we expected that the studied organizations would adapt to these developments, by increasingly using outsider strategies in their advocacy work.

Our results show, however, that among the local branches, there still seems to be a preference for influencing policy through direct contact with politicians. However, according to some respondents, this has not given them very much leverage in the policy-making process. The corporatist structures of the healthcare sector, such as participation committees, are also a way for the local branches to participate, although experiences of the benefit of such participation vary among respondents. Despite recent reforms to emphasize individual opportunities for influencing healthcare, it seems that the structures for group representation linger. Outsider strategies are rare and mostly used to recruit members, not for influencing politics.

The two individualization processes studied here were to very different degrees impacting the organizations. The interviewed board members had not considered the individualization within healthcare, mainly carried out through marketization reforms, as affecting their advocacy work. The individualization process within the voluntary sector, however, is undoubtedly present in the minds of the board members. Modern life's disruptiveness and short-term commitments, as illustrated by Hustinx and Lammertyn (2003), are clearly relatable to the board members. For the POs, this mainly takes its shape in passivity and disinterest in collective work. Mentions of the decrease in membership numbers and the existing members' inactivity seemed to affect all sides of the organization – including their advocacy work. These results, combined with observations from previous research on the younger generation's disinterest in the kind of volunteering offered by the traditional CSOs, indicate a worrisome future (Amnå, 2007; Skocpol, 2003; Werkö Söderholm, 2008). The demographic issue is of special concern for POs as potential members mainly are older.

Although these trends are painfully present, the adjustments we would expect and that also are broadly discussed in the literature in the field – such as creating a more flexible environment enabling short-term volunteering – do not seem to be conceivable alternatives for these local branches today. They do what they can to be seen and to get new members, but there are no plans to change membership forms into more flexible alternatives or to rationalize their activities by using modern technology such as social media (see Papakostas, 2011). Because we are studying only local branches, we cannot determine the degree of professionalization and centralization in the organization, and what effects these might have on the local branches.

Our study shows that local branches do not actively adapt their routines to the changing environment, as was an expected response for these organizations to carry out their representative role successfully. Although some individual respondents do identify challenges connected to individualization processes, we cannot from our interviews establish a systematic pattern of organizations actually acting on these challenges by changing their strategies and routines.

Our interviews show how the local branches' handling of the two-front individualization appear to be connected. The challenges brought by the passivity in civic engagement seem to keep the organizations from reflecting on the implications of the changing power structure of the Swedish healthcare system. For this reason, departing from the logic of previous research on these changes, they might be missing the opportunity to find new ways of representing their members that are needed to develop an active and influential advocacy role in the more individualized healthcare system.

This weak tendency to change may be caused by different reasons, varying between a lack of recognized need, will to, and resources for change. A related, explanatory factor to the low degree of changes in this, de facto, changing environment is path dependency and organizational inertia. According to sociologist Stinchcombe (1965), organizations created in the same time will have the same structure and continue to be alike in the future. Although this study focused on the Swedish popular movement tradition, the results may still be relevant for CSOs formed in other contexts with other ideas of the ideal organization.

The weakness of the local POs leads us to ask what they actually bring to the table in terms of local democracy and governance. The POs were established in a historical phase with the purpose of helping individuals to be heard when the welfare state was too large and rigid and healthcare was paternalistic, with few opportunities for individual patients to influence services. These organizations might not be as relevant at a time when the welfare state is shrinking and the individual is more prioritized. Is it possible that, in this new time, patients experience sufficient local influence without having to mobilize collectively?

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