

Working paper Third Sector changes: the case of the patient movement in the Netherlands

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Introduction

‘The Dutch breast cancer association (BVN) was founded in 1979 and initially only engaged in peer support,’ reflects the chairwoman of the association. Women were supporting their peers by visiting each other in hospitals to help them come to terms with their condition. Throughout the years the activities of the BVN have increased tremendously, especially on the subject of interest representation. ‘In 1996 interest representation took shape.’ These interest representation activities got an extra boost with the introduction of the new health care system, based on regulated competition, in 2006. ‘With the introduction of the new system the minister of health care said: the patient has to be the driving force of the new quality arrangement. And the patient has to be as powerful as an equal third party at the decision making table.’ Although the chairwoman of the BVN points out that they are not an equal party yet, the organization can now participate in many decision making processes. They participate in medical guideline development, in improvement projects in hospitals, in the development of the *Breast Cancer Monitor* (a database which can be used by patients to help them choose their health care provider), negotiate and consult with health care insurers, conduct investigations when they receive troubling information from their members and lobby parliament to change policy.

The activities, but also the organization of the BVN changed tremendously over the years. It is one of many patient organizations in the Netherlands, most of which are changing or try to change in similar ways. These changes are intertwined with the Dutch health care reforms in which a *third party role* has been attributed to patient organizations, next to health care providers and health care insurers. These changes therefore have to be analyzed in the context of these reforms, which resulted in the Health Insurance Act in 2006 after a reform process that started in the late 1980s. The Health Insurance Act introduced a system of regulated competition, in which, according to the ministry of health: ‘the patient – the insured party – really occupies centre stage’ (Ministry of Health Welfare and Sport 2006). According to policy makers individual patients have to become actively involved in health care to turn the new system into a success. Patients have to choose their own health care insurer, their health care provider, and they have to be an active participant in all types of other decisions concerning their care (Grit, van de Bovenkamp et al. 2008). On the collective level, policy makers expect organised patients to perform many activities as well (see for instance TK16771 no.1-2, 31, 22702 no.11, 27807 no.3, 20, 29214 no.24). They have to be a third party, which means that patient organizations have to focus much more on interest representation in all kinds of decision making processes than they did before. At the same time the other parties in the health care sector (e.g. governmental organizations, health care insurers, and health care providers) started to provide services comparable to the prior activities, peer support and providing information, of patient organizations. These changes have consequences for their position as third sector organizations. They are moving into different domains which again necessitates them to act differently. In this paper we will explore patient organizations, as third sector organizations, these changes they went through and their consequences more in depth. We will answer the following research question:

How did the role and activities of the Dutch patient organizations change in the context of the Dutch health care reform and what have been the effects of these changes?

In the first section of the paper we will describe the methods used to answer this question. Secondly, we will go into the characteristics of third sector organizations. Thirdly, we will

shortly describe the context in which the changes of the patient movement came about. This is followed by a description of the history of the Dutch patient movement and their activities today. The changes these organizations made will be further analyzed drawing on a model of third sector organizations. After this we will reflect on the consequences of these changes. We will end our paper with a discussion in which we will elaborate on the implications of these results.

Methods

To answer the research question we used several research methods. First of all we interviewed 45 people that are involved in these changes in health care in the Netherlands. We interviewed representatives of patient organizations, insurers, health care providers, supervisory bodies and the ministry of Health. Subsequently we analyzed policy documents and the literature on the subject of the role of patient organizations and their activities. In addition we studied relevant literature on third sector organizations, intermediate organizations and social capital.

The third sector: a hybrid environment

The Dutch health care sector is a hybrid sector. With its public, private and professional character it is positioned in between the domains of the state, market and community (Meurs and van der Grinten 2005; Helderma 2006; Bal 2008). This area can be described as the third sector. The third sector comprises different organizations and movements. In general these are private *nonprofit* or *nongovernment* organizations, social movements, volunteer groups, cooperatives, et cetera (Brandsen, Van de Donk et al. 2005). Within the field of health care they are professional groups, providers, and patient organizations.

These organizations seem to have just a few similar characteristics (Giddens 1994; Brandsen, Van de Donk et al. 2005), but they all can be recognized as ‘caring’ organizations. Yet, these are still vague terms; vagueness however may be a defining characteristic of the third sector. The vagueness is due to increasing boundary problems between the area in between the domains of the state, market and community and the surrounding domains itself (Brandsen, Van de Donk et al. 2005). The third sector is also known as the intermediate area. According to Evers all organizations in that area relate in one way or another to the other sectors (Evers 1995), causing the blurring of sectoral boundaries. By integrating usually separated rationales and functional orientations from state, market and community, third sector organizations often have a *hybrid* character (Evers 1995; Van de Donk 2001; Brandsen, Van de Donk et al. 2005). Those mixed elements from the ideal typical domains are referred to as hybrid forms. Hybridity thus refers to the mixture of resources, rationales, steering and coordination mechanisms from the different sectors. Within the class of organizations that share this element, various analytical types can be distinguished, which are shown in figure 1 (Van de Donk 2001; Brandsen, Van de Donk et al. 2005).

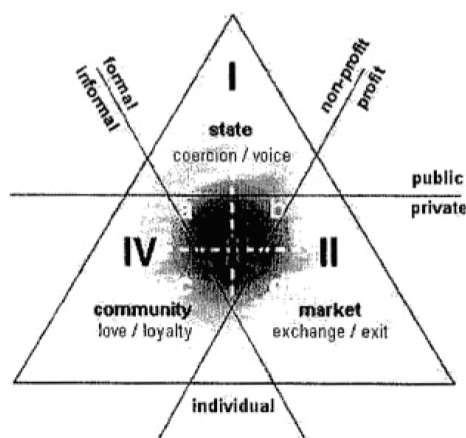


Figure 1. The four areas within the third sector (van de Donk 2001)

At the centre of figure 1 the quadrants A, B, C and D refer to four types of third sector organizations. Brandsen, Van de Donk and Putters (2005) described the different types of organizations as follows (p. 751-752):

- (A) The first type comprises organizations where caring for others concerns the 'indirect other', for example the environmental movement. These organizations often operate near the political domain, since they mostly attempt to use political procedures.
- (B) The second type is also close to the political system. These organizations are unions, umbrella organizations that care for more tangible others, representing the interest of their members.
- (C) The lower left quadrant of the circle comprises those organizations providing care within communities. They often originate in families or personal networks and operate in open or closed communities, such as neighbourhoods.
- (D) Organizations in the lower right quadrant are characterized by higher degrees of professionalism and a range clients/beneficiaries beyond communities from which they sprang. Not surprisingly, they are closer to the market domain, as they often provide forms of care also provided by market enterprises.

The literature assigns several positive characteristics to this sector. As we can see all third sector organizations are supporting the public interest, they function as alternative service providers, providing services that are not provided by the market, the state or the community (Evers 1995). They create opportunities to solve social problems (Backman and Smith 2000). Zijdeveld stresses the importance of keeping the state, civil society and the market in balance for the functioning of a viable democracy (Zijdeveld 1999). These organizations can also be important for democracy since they are a way for people to let their voices be heard, when they try to influence public policy (Evers 1995; Backman and Smith 2000; Couto 2001; Warren 2003). Public virtues such as participation, solidarity and concern are also fostered in these organizations, Zijdeveld speaks of them as *sources of morality* (Evers 1995, van de Donk 2001; Zijdeveld 1999). In relation to this, authors point out the fact that social capital is especially created in this sector (Evers 1995; Backman and Smith 2000; Putnam 2000; Van de Donk 2001). Putnam underscores the importance of societal organizations or societal enterprises reasoning that those organizations are important for the generation of social capital and by doing that for a strong democracy and a well functioning economy (Putnam 2000). Putnam argues that societal organizations are the 'social multipliers', strengthening society's immune system (ibid.).

The Dutch health care reform

We will highlight the most important health care reforms first, because if we are to understand the impact of the changes in government policy on the third sector, we must understand the dynamics of the relationship between the state and the third sector first (Taylor and Bassi 1998).

Since the 1980s many well developed countries championed market oriented reforms and many government activities were privatized (Kramer 2000; Smith 2002, Helderma, 2007). The shift away from the domain of the state which was present in many areas within the public sector towards the domains of the market and community is defined as the shift from government to governance (Van Montfort and Oude Vrielink- Van Heffen 2006). The Dutch health care reform can be seen as part of this trend in which steering and regulation by semi-public parties, public-private partnerships, private stakeholders, professionals and / or citizens themselves became more important. The reforms in Dutch health care were also aimed at the introduction of competition and market principles. This process started at the end of the 1980s with the advice of the Dekker Committee (Commissie Structuur en Financiering Gezondheidszorg 1987) and ended with the introduction of the national Health Insurance Act in January 2006. The policy perspective of more competition and entrepreneurship has not changed since 1987. Although the policy changes in this period were all in the similar direction of a system based on regulated competition, many ministers struggled with their

implementation. Because the government has to safeguard the public goals in health care (accessibility, quality and financial sustainability) on constitutional grounds, the government still regulates the market, among others by legislation, budgets and supervision.

The goal of the health care reform was to change the health care system from a system based on the supply side towards a demand-driven system. The empowerment of organizations, professionals and citizens at the decentral level is the fundamental idea of the health care reform (Putters, Den Breejen et al. 2008). One important aspect is giving patients or health care ‘consumers’ more influence on (the organization of) the care they receive. This is built on the assumption that patients can and will play a more active role than they used to. This active role gives patients/consumers/citizens¹ more control; in health care, this is often described as the *empowerment* of patients. Patients have to make decisions on which health care insurers to choose and which health care provider to go to when in need of medical attention. On top of this, patient-centred medicine has become a dominant paradigm in modern health care, which puts a strong focus on patient participation in clinical decision making (Bensing 2000), so patients also have to participate actively in decision-making in their own care process. These changes make health care more focused on the individual patient. Still, at the same time it is recognized by policy makers that patients cannot do all this alone and their collective interests need to be safeguarded as well. Several patient acts were created which legally strengthened their position. There are for instance patient acts that regulate the health care provider- patient relationship (Wgbo), complaint possibilities (Wkcz) and client council’s influence on the policy of an institution (Wmcz). Secondly, it is recognized that patients need organizations that represent their interests and make sure that conditions are set to enable them to play their active role (van de Bovenkamp, Grit et al. 2008). Many organizations such as the ministry of health, welfare and sport, governmental supervisory bodies, research organizations, health care providers, and health care insurers develop activities that fit into this category (Becher, Vandebroek et al. 2008; van de Bovenkamp, Grit et al. 2008). However patient organizations especially are expected to play an important role in safeguarding the interests of patients. They are considered to be the *third party* in health care, next to health care providers and insurers. Yet, this third party role was not why most of these organizations came into being. Their activities, their organizational structure and in some cases their ideology have changed considerably to be able to play this third party role.

The patient movement in the Netherlands

In the literature patient organizations are described as a social movement (Nederland, Duyvendak et al. 2003; Allsop, Jones et al. 2004; Epstein 2008). This movement in the Netherlands consists of a variety of organizations. It comprises over 300 organizations, which were mostly founded from the 1970s onwards (Trappenburg 2008). Together they have about 2 million members (Oudenampsen, Kamphuis et al. 2008). Most of these organizations are disease specific, there are around 200 of them (Berk, van der Steeg et al. 2008). Examples of which are the Breast Cancer Association, the Pancreas Association and the Dutch Association of Kidney patients. These organizations often concentrate on patients and their families, but there are also family member organizations, such as Ypsilon, an organization for family members of patients with psychotic episodes.

Some of the disease specific organizations have organized themselves in disease group umbrella organizations. The Breast Cancer Association and other cancer organizations for example, are part of the Dutch Cancer Federation. There are also regional umbrella organizations which take care of general patient interest representation on the regional level (www.zorgbelang-nederland.nl). In addition there are national umbrella organizations; the NPCF (Dutch Patient and Consumer Federation), the CG Raad (Chronically ill and Handicapped Council), the CSO (Central Elderly Collaboration) and the Platform GGZ

¹ In the remainder of this paper we will use the term patient, unless one of the other roles are specifically relevant.

(mental health care platform), that perform this task at the national level. The members of these umbrella organizations are not individual patients but other patient organizations.

Patient organizations nowadays develop activities directed at improving the situation of individual patients (peer support and information) as well as at patients as a collective (interest representation, third party role). Examples of these sets of activities can be found in table 1. In this paragraph we will describe the history of these organizations and show that while they were founded to organize activities directed at the individual, activities directed at patients as a collective have become especially important in recent years.

Individual	Collective
<p><i>Peer support</i></p> <ul style="list-style-type: none"> - Telephone helpdesks - Email-contacts - Internet forums - Self help groups <p><i>Information</i></p> <ul style="list-style-type: none"> - Leaflets - Websites - Periodicals - Telephone helpdesks - Email contacts - Theme meetings 	<p><i>Interest representation/ third party role</i></p> <ul style="list-style-type: none"> - Consultation on government health care decision making - Participation in medical research decision making - Participation in guideline development - Participation in improvement projects of health care providers and insurers - Negotiation and consultation with health care insurers - Etc.

Table 1 Activities of patient organizations

The early years of the patient movement

The Breast Cancer Association introduced in the beginning of this paper is an example of the fact that many patient organizations were founded to organize contacts between fellow sufferers (see also Trappenburg 2008). Organizing these contacts has always been an important job of many patient organizations and is seen as an important constant in their tasks over the years (Verkaar 1991; Oudenampsen 1999; Oudenampsen, Nederland et al. 2007; Oudenampsen, Kamphuis et al. 2008; Trappenburg 2008). Another reason for organizing themselves, and that is closely connected to this peer support, was providing information about among others the condition, the organization of care and available treatments to other patients (Verkaar 1991; Oudenampsen, Nederland et al. 2007). Activities in short directed at individual patients. Most patients organized themselves because they needed this peer support and information, which they could not find elsewhere. So these organizations came into being to provide something that was not provided by other actors.

Whereas peer support and providing information were the most important reasons for many patient organizations to organize themselves, some had more outward looking goals. Client organizations, in mental health care, which can be described as protest organizations, are the most important example of this (Rijkschroeff 1989; Verkaar 1991; Trappenburg 2008). In the 1970s they started to protest against the ‘inhuman’ treatment conditions in mental health care and the unequal power relation between clients and health care professionals (www.clientenbond.nl; Rijkschroeff 1989). Their goal was to make health care more socially oriented and democratic (ibid.). They, together with some organizations for the handicapped who focussed on a social model of disability, did try to change the health care system by collective interest representation. However, this task was not taken up by a large part of the patient movement yet, they mostly concentrated on peer support and providing information, some of them doing some interest representation in addition. This changed over the years however, influenced by government policy that stressed the third party role as a countervailing power to health care insurers and health care providers, as the role of the

government itself was to become less important (TK 16771 no.1-2, 31,TK 27807 no.3, TK 29214, no.24).

Towards a third party role

Patient organizations have increasingly taken up the task of collective interest representation and try to influence decision making in several ways. They organized themselves in umbrella organizations on the regional and national level in the 1980s, after such was proposed by the Dutch government (TK16771, no.2). These umbrella organizations could be addressed by providers, insurers and government for issues superseding a particular disease or condition.

These national and regional umbrella organizations were not the only ones developing activities in the area of interest representation though; disease specific organizations became more and more active in this regard as well. Respondents report on many different activities in this regard. Next to the importance of democratic and legitimate decision making, the basis for these activities especially is the contribution of the patient perspective or the experiential knowledge: the knowledge these organizations have of living with a certain condition and of the contacts with the health care sector (Blume and Catshoek 2001; van de Bovenkamp, Grit et al. 2008). Patient organizations are increasingly consulted on decision making on research proposals and are sometimes asked to be involved in decision making on the research priorities for the years to come (Klop, Kammen et al. 2004; Caron-Flinterman 2005; Smit 2005; Trappenburg 2008). Additionally, representatives of patient organizations can participate in medical guideline development, where they are asked to contribute the patient perspective on the necessary treatment and care for specific conditions (Cavelaars, Franx et al. 2002; Veenendaal van, Franx et al. 2004; Trappenburg 2008). Patient organizations also have contacts with health care providers, to develop health care improvement trajectories (van Hooff and Bochart 2007; de Wit, Mul et al. 2008). The list of participation possibilities goes on, patient organizations are involved in the development of the CQ-index; an instrument to measure the experience of patients with many aspects of care, they are consulted in the policy process by the ministry of health and parliament, have seats in several advisory committees and consult with supervisory bodies (van de Bovenkamp, Grit et al. 2008). The introduction of the new health care system in 2006 emphasized these participation possibilities once more and also introduced another task for patient organizations: they are given the possibility to strike deals for their members for collective contracts with health insurers (Bartholomee and Maarse 2007). In January 2007 forty patient organizations reported on such collective contracts with health care insurers (www.npcf.nl). In addition there are contacts between health care insurers and patient organizations to talk about health care purchasing (van de Bovenkamp, Grit et al. 2008). Over two thirds of disease specific patient organizations report on having contacts with health insurers in 2006 (Oudenampsen, Nederland et al. 2007). These developments have gone quite fast: the additional tasks of disease specific organizations have especially started from the second half of the 1990s onwards.

So whereas many organizations started out with providing information and peer support to individual patients they can now consult and enter agreements with policy makers, health care professionals, health care insurers, researchers and intermediary organizations to represent the collective interests of patients. This can be considered an important change in their activities. At the same time there are also changes in the field of their core tasks: peer support and providing information, here other parties are entering the field. Since these changes could also have important consequences, we will shortly describe them.

Competition on core tasks

The third party role of patient organizations focuses on influence through the use of voice. However, in the new health care system a lot is expected of individual patients using the exit option (Hirschman 1970). They have to choose health care providers and insurers (Grit, van de Bovenkamp et al. 2008). To do this they need information and this information is available at many places today. There is a government funded website www.kiesbeter.nl (choose better) on which consumers should be able to find: answers to all their health care questions (Loon

and Tolboom 2005). Although much of the information that should be on this website is not available yet, it is expected to be in the years to come. Then people can compare the results of health care providers on several quality indicators but also on the basis of patient experience research. In addition there are several other (commercial) websites which provide health care information, Dutch newspapers and magazines provide hospital top 100s and health care providers and insurers are increasingly providing potential clients with information themselves (van de Bovenkamp, Grit et al. 2008).

The strong focus on patient centred medicine in recent years has been reason for some health care providers to provide services that can be considered peer support as well. Group consults are an example of this. Group consults consist of a series of consults with a group of about 15 patients. This way they do not only receive more information from their health care professional (since these consults are longer than an individual consult and several professionals with different expertises are present), but they also give patients the opportunity to learn from each other (www.cbo.nl; Seesing, Janssen et al. 2006). Other initiatives are taken as well in which peer support is provided. Health care providers have internet forums for their clients on which they can share experiences of their care and condition for instance. An example of this is the IVF clinic in Nijmegen which has introduced a virtual clinic, part of this is a forum on which patients can share their experiences. Other initiatives made possible by ICT developments provide possibilities for peer support also. Most patient organizations have ceased this opportunity. They have internet forums or guestbooks on which patients can share experiences. But this can be done by unorganized patients as well, for example by using blogs and wiki's (Grit, van de Bovenkamp et al. 2008).

Patient organizations still provide peer support and information to their members and there is still a lot of demand for these activities (Oudenampsen, Kamphuis et al. 2008). There are also the first signs that these activities directed at individual patients are deemed less important, though. The Diabetes Association for instance does not 'officially sell peer support anymore, when the new mission is put into practice'. Although we did not find other instances in which peer support was denounced like this, it is important to note that similar activities are increasingly being provided by other actors. The increased emphasis on making health care more attuned to individual patient preferences, has caused other parties to provide activities comparable to the ones directed at individual patients of patient organizations. This, combined with the increased pressure to become the third party in health care, could further change these organizations in important ways.

Consequences of the changing activities

The changing activities of the patient organizations have several consequences. In this paragraph we will examine their institutionalisation and their professionalization.

Institutionalisation

Most of the interest representation activities of patient organizations in the Netherlands take place at the decision making table (Nederland and Duyvendak 2004; Trappenburg 2008; van de Bovenkamp, Grit et al. 2008). Representatives of patient organizations also talk about examples of lobby activities and the use of the media to accomplish certain goals, but the bulk of their participation activities consist of formal decision making processes. As a result they moved further to the political system and show signs of institutionalisation. This institutionalisation on the one hand gives them the opportunity to influence decision making. On the other hand there is the danger of losing their identity and alienating their members, since they are forced to compromise. Some of our respondents even point out that for some organizations sitting at the decision making table has become a goal in itself. The fact that patient organizations can become hedged in by taking part in decision making in this way is also shown by the solution to the problems in health care that are signalled by them. De Swaan (1989) shows that in a process of proto-professionalization people attributed higher value to professional (for instance medical) knowledge and as a result started to use professional terms to define daily events (de Swaan 1989). Similar processes can be seen in our case study. One of the main objectives of the NPCF for instance was the introduction of

the Health Consumer Act, in which the judicial position of patients would be strengthened. These consequences of institutionalisation are of course not reserved for patient organizations, but for other pressure groups that try to influence decision making by taking part in official decision making procedures as well (Akkermans and Nobelen 1983; Williamson 1989; WRR 2004; Cawson 1986).

Professionalization

Part of their institutionalisation is the professionalization of patient organizations. To comply with these interest representation tasks patient organizations continuously needed and were pressured to professionalize (Verkaar 1991; Nederland and Duyvendak 2004; Oudenampsen, Kamphuis et al. 2008; Trappenburg 2008). The call for professionalization stems from the fact that it is recognized that patient organizations are not an equal party yet and therefore action should be taken towards making them so (Nederland and Duyvendak 2004; Goudriaan and Goris 2007; Oudenampsen, Kamphuis et al. 2008).

The layered structure of the movement is one example of this professionalization. Another is the education of active volunteers (Trappenburg 2008), and the selection procedures for volunteers. Whereas previously anybody could become a volunteer, now many of the disease specific patient organizations search for 'the right volunteers' who have to have certain qualities to perform complicated tasks. Furthermore, many representatives of patient organizations are convinced that these organisations cannot be run by volunteers alone, and that professional employees are needed. Still, employing professionals is not an option for about half of the organizations due to financial constraints (Berk, van der Steeg et al. 2008). The umbrella organizations do work with professional employees. The NPCF also has 'professionalized' its board, which does not just consists of people with experiential knowledge anymore but also of business administrators and economists (www.npcf.nl). These internal changes can also contribute to the shifting position of third sector organizations (Backman and Smith 2000). To make the professionalization process possible patient organizations have been structurally subsidized by a government fund (PGO Fund) since 1996 (TK 27807 nr.3, 29214, nr.24). This fund was assigned the task to strengthen the patient movement. In order to apply for subsidies of this fund patient organizations have to be active on the three areas described earlier: peer support, information provision and interest representation. Another sign of their professionalization is the increased importance of work plans for the years to come and annual reports in which they have to be accountable for outsiders and the PGO fund.

Many representatives of patient organizations feel they have to professionalize further, though some of them do not agree with this. They argue that this professionalization is 'not what it is about', and point out the importance of activities directed at the individual level: peer support and sharing information. This minority does also oppose the outside pressure to professionalize them and the attitude towards them, which according to the chairman of the Lymph node cancer association can be described as follows: 'they are a bunch of willing amateurs and we have to educate them a bit and professionalize them a bit.' Other actors, such as insurers, providers and government organizations do indeed emphasize the need for patient organizations to professionalize further (Goudriaan and Goris 2007). This professionalization could in turn contribute to the institutionalisation of these organizations since it focuses on being able to talk as an equal party at the decision making table.

The changing activities therefore set of changes in the organization and position of patient organizations in the health care sector. Changes which again could contribute to reinforcing the changes in activities described earlier. During our interviews it became clear that especially professional employees of patient organizations stress the importance of interest representation activities. Although most of them acknowledge the importance of the other activities, they feel that in the future especially their interest representation branch deserves further attention. Of course increasing these interest representation activities would in turn also increase the call for professionalization and could further their institutionalization. These changes therefore develop in a circular motion.

Third sector changes

After describing the changes the Dutch patient movement went through we will now discuss these changes in terms of the third sector model that was introduced in the beginning of the paper.

Despite of the fact that the Dutch health care system is placed under private law since 2006 the government is still responsible for the safeguarding of the public constraints. Based on the constitution the responsibility of the government covers those constraints, like delivery, accessibility and financial sustainability of health care. On these constitutional grounds the government will always be involved in health care, putting the sector in the third sector. However, by shifting to private law, the executive part of health care, the health care providers and health care insurers, shifted more towards the domain of the market, or in this framework's terms towards the lower right quadrant (D) in the figure presented earlier (figure 1).

However it remains unclear what this shift really means. The hybridity of the third sector lies at the heart of this unclearness, because it is mainly because of the mixed elements that it is hard to say what it means to be in one part of the figure or another (Brandsen, Van de Donk et al. 2005). What is clear however, is that the organizations that are shifting because of the system changes have to search for new organization and coordination mechanisms (ibid).

Patient organizations have, as most organizations in the third sector, an intermediary role: they have the task of combining a number of cross-sectoral relationships (Evers, 1995). In general, these relationships exist between these organizations' members and public authorities; between market-related economic constraints and their specific social goals; and between the professionals and their clients in informal settings, acting as 'co-producers' (ibid.). To comply with the difficulties of intertwining the cross-sectoral relations the organizations have to balance between the different goals and interests, and the dilemmas that come along with this (Van de Donk 2001; Brandsen, Van de Donk et al. 2005; Putters 2006). When we analyze the shifts patient organizations in the Netherlands made in terms of the model by Van de Donk (2001), they could in the beginning of their existence be categorized as type C third sector organizations. Patients organized themselves to provide a type of care in closed groups. Some of their activities (and in some cases most of their activities) can still be placed here. However, the changes in activities also cause changes in terms of this model. On the one hand, they have shifted with their collective interest representation activities more towards the political system, and they therefore can be positioned in the upper right quadrant (B). On the other hand, they, or at least some of their activities earlier performed close to the community (peer support and information), can now be positioned in the lower right quadrant (D), where market oriented third sector organizations and market organizations operate.

An important change patient organizations made therefore is a move from private to public (on the private-public axes). This is especially interesting since government policy in health care also shows a move from public towards private, with the emphasis on the role of the individual patient or health care consumer and the changes of other parties in health care in reaction to that. The health care reforms therefore cause a lot of dynamism and even contradictory shifts.

Salamon identifies several reasons why third sector organizations come into being, which can also be used to analyze the changes these organizations go through. First of all this can happen because of changes from below, from ordinary people and their organizations themselves. Second of all they can be encouraged from the outside by for instance charges or social groups. Thirdly they can be supported from above, in this case governments encourage them to become active in certain ways to accomplish certain policy goals. Salomon uses the Reagan and Thatcher administrations as examples of this; they strongly supported activities in civil society to cut back government spending (Salamon 1995).

Many patient organizations' originated because of patients themselves felt the need to organize, some of them were encouraged to do so by health care professionals (Trappenburg

2008). Their hybridization is also for a large part due to governmental support (support from above). The Dutch government did not only have a positive attitude towards patient organizations (Nederland, Duyvendak et al. 2003), it also strongly influenced their organization and activities in order to accomplish certain policy goals (Trappenburg 2008). Trappenburg shows that many activities taken up by patient organizations were activities proposed by the Dutch government. They also organized themselves according to government wishes. The foundations of regional and national umbrella organizations are examples of this. Government even interfered with the organizations ideology, urging them to be more critical towards health care professionals. The reason for this interference was an attempt to get more control over health care (expenditures). Patient organizations were useful in diminishing the power of health care professionals who had been very successful in the past to frustrate government policy (ibid.).

With these changes the position of patient organizations has become a complex one; developing activities in the community but also in the political arena and in the market. The patient organizations are thereby facing the dynamics of the health care sector as a whole.

Discussion

We will now turn to some of the tensions that these changes bring about and will shortly put these findings in the broader perspective of third sector organizations.

Influence on decision making

As was said, third sector organizations are subject to outside pressures, which they have to respond to one way or the other (Nutt and Backoff 1995). Patient organizations have responded to their changing environment in a way that could enable them to influence decision making and represent the interests of their members. They saw and in some case fought for participation opportunities and they grabbed them.

Furthermore, third sector organizations can help make public policy a success (Pestoff 1992). Although there is still little known about the functioning of the new health care system, the role of patient organizations could contribute to its success. Dees et al. (2003) also point out that this 'sector bending' could potentially have advantages such as a higher efficiency, more appropriate resource allocation and the creation of more sustainable solutions (Dees and Andersen 2003).

The role of patient organizations in decision making could also make these decision making processes more democratic, since a forum for public debate is created (Taylor and Burt 2001), giving a traditionally weak party in health care a voice in decision making. Third sector organizations can play a democratic role not only by creating a forum for public debate and being a means for citizens to influence decision making, but also by developing democratic capacities and values of citizens (Warren 2003). At the same time there are some dangers identified to this type of organizations concerning democracy (Warren 2003; Trappenburg 2008). Warren argues that when the means of the different sectors blend (power, money and norms) there are democratic dangers since these organizations cannot be held accountable by the public and they can cause differences between groups in possibilities to exert influence and the provision of public goods (Warren 2003). This accountability question is also important for patient organizations, as we will discuss later. Although their possibility to influence decision making could cause new differences (for instance between patient groups but also between patients and tax payers), since the other parties in health care always had a strong position and government never could make decisions alone in this sector (Meurs and van der Grinten 2005) this does not have to be considered to be problematic.

Although patient organizations today have more opportunities to influence decision making than they did before, they do find themselves in an especially vulnerable position. Other than, for instance unions, they have little bargaining power. Other parties do not really need them to stand behind the decisions being made. This is most likely also a reason why patient representatives report on not being an equal party yet. Furthermore, their participation is in danger of symbolic use (Epstein 2008). Harrison et al. (1998) talk about *playing the user card*

to describe this practice. When patient input is consistent with the opinion of decision makers it can be used to legitimize decisions. When their input deviates from their opinion, decision makers can question the representativeness of these groups or the knowledge they have (Harrison and Mort 1998). Respondents acknowledge the danger of the instrumental use of their participation. Our respondents also acknowledge that they are not an equal party yet, and therefore more support and professionalization is necessary but it is questionable whether they ever can be an equal party. They have to compete with parties that have a lot of resources: insurers (money), professionals (knowledge) and government (power). The danger is then that they become a tool to accomplish goals of other parties (Gidron and Katz 2001; van de Bovenkamp, Grit et al. 2008). Insurers, providers and researchers can claim an increased legitimacy when patients have been invited in the decision making process to accomplish their own goals (attracting new costumers, patients, research funds). The influence of government is as we have seen even stronger and can be and is used to accomplish certain policy goals. Patient organizations are therefore an example of a non profit organization that has to think about its relationship with government (Najam 2000).

Social capital

One important contribution of third sector organizations is creating social capital (Zijderveld 1999; Backman and Smith 2000; Muntaner, Lynch et al. 2000; Putnam 2000; Van de Donk 2001). According to Van de Donk (2001) this social capital is especially created in *type C* third sector organizations; the type patient organizations originally started out as. Social capital is also created in patient organizations. Although according to Putnam (2000) organizations that are outward looking and bring people into contact with other people that are *not like them* will create bridging social capital are to be valued more. Contacts with similar people create bonding social capital which does not have the same positive effects according to him. However, becoming active in more outward looking organizations may not be an option for certain groups of patients (Trappenburg 2008). Our research showed that it can be especially important for patients who have difficulty staying active in society due to their illness or condition, to become actively involved in a patient organization. Becoming active in this way can be a means to feel useful again. A patient organization brings them together with fellow sufferers and also with other types of people that an active member can meet in the described decision making processes and can become a very important part of their lives. These activities could also be a first step towards reintegration in work (Pestoff 1992). With the continuous pressure to professionalize these opportunities for certain patients that want to become active in this way could decrease though. As we already pointed out patient organizations are starting out to search for 'the right volunteers' which often means highly educated or in any case able to understand and contribute to complicated decision making processes. They also hire professional workers to take on certain tasks, which could cause a further reduction in social capital (Backman and Smith 2000). Furthermore, social capital and the trust it creates is also very important in the patient-doctor contacts (Coleman 1990). Professional patient organizations which critically look at health care professionals could also have negative consequences for this relationship.

Legitimacy

The professionalization and institutionalisation raises additional questions concerning legitimacy. When 'professional' patients or employees of patient organizations provide input on what the patient wants on certain subjects questions can be raised about their representativeness and therefore the value of their input (which as we saw earlier can also be used against them). They have a lot of knowledge 'normal' patients do not possess which could influence their interests (Epstein 2008). For instance *the patient participation in scientific research guide*, a publication of ZonMw, the organization charged with dividing medical research budgets in the Netherlands, has made a competency list, consisting of among many other criteria: knowledge of research policy, guidelines, consultation with government, health care professionals and pharmaceutical industry (Vossen 2006). Respondents furthermore told that patient organizations are not always able to research what

it is their members want (see also Berk, van der Steeg et al. 2008). The layered structure the patient movement now consists of causes similar types of questions. Our interviews showed that members of umbrella organizations do not always recognize themselves in or agree with them, although these umbrella organizations do claim to speak on behalf of their member organizations.

This legitimacy question was not so much an issue in the early days of patient organizations, since they did not try to influence decision making in this way. Today however, they are asked to contribute 'the patient perspective' which causes questions surrounding their legitimacy to come to the fore.

Conclusion

We can conclude that the changing activities and the effects of these changing activities raise important questions for patient organizations. Although as we said in the beginning of the paper, third sector organizations always show ambiguity, the changes patient organizations went through which caused their positioning within both the upper right and the lower left and right quadrant makes the behaviour of these organizations more ambiguous and therefore more complicated than before. They are moving away from their original position and the values that are attached to that position. Their move into other domains brings with it the tensions just described and organizations have to think about how to respond to these tensions. Moving into the political and the market domain demands a different course with different goals and strategies, also because it brings them into contact with other actors that have interests of their own. The strong influence that especially the government exerts on patient organizations to accomplish policy goals on the one hand strengthened their position on the other hand does this not automatically coincide with the preferred course of the patient movement. The same can be said of the goals insurers and providers want to accomplish with patient participation. Patient organizations are therefore at risk of being put to instrumental use (van de Bovenkamp, Grit et al. 2008). This makes it all the more important that they think about their own goals and their preferred relationship to these other actors. Do they want to change in the directions other actors want them to and do they want to participate in processes to achieve the goals of other parties? Since patient organizations are still just that, organizations of patients, they should foremost discuss this amongst themselves. Research into the preferences of the organizations' members is probably necessary to accomplish this, seeing that representatives of patient organizations have different ideas about this and often do not really know how their members think about such subjects.

Patient organizations do not only have to think about their goals, but also about their strategies, for instance what actor to form an alliance with (health care professionals, insurers, government) at what times on what subjects. And also what activities they want to leave to other actors: patient organizations after all do not have to be active on every subject of health care. There are also other relevant issues concerning the decision on proper means to accomplish certain goals. When patient organizations want to stay active on the subject of interest representation, which we can say on the basis of our interviews and the literature is very likely, they could also think about other strategies than participating in formal decision making processes, such as the use of more active protest strategies. In addition, it is important for them to approach the subject of professionalization with some reserve. This professionalization will be at the expense of the experiential knowledge the contribution of which patient organizations were invited for in the first place, which they themselves still refer to and which is the basis of their legitimacy. Furthermore, this professionalization could have negative effects on the development of social capital.

In this paper we have tried to show what changes third sector organizations can go through and what can be the effects of such changes, using the patient movement in the Netherlands as a case study. Although we used this single case study we feel that it could also provide insights for other cases. Shifts in the third sector domains have important consequences for these organizations that could easily go unnoticed, since these processes often develop over some time. It is unlikely that these shifts and the hybrid character of third sector organizations are going to disappear (Brandsen, Van de Donk et al. 2005). However, it is important that

these organizations as well as policy makers think about these consequences and adjust their strategies and their activities to them.

References

- Akkermans, T. and P. W. M. Nobelen (1983). Corporatisme en verzorgingsstaat. Leiden/Antwerpen, H.E. Stenfert Kroese b.v.
- Backman, E. V. and S. R. Smith (2000). "Healthy Organizations, Unhealthy Communities?" Nonprofit Management and Leadership **10**(4): 355-373.
- Bal, R. (2008). De nieuwe zichtbaarheid: sturing in tijden van marktwerking. Rotterdam, ErasmusMC.
- Bartholomee, Y. and H. Maarse (2007). "Empowering the chronically ill? Patient collectives in the new Dutch health insurance system." Health Policy **84**(2-3): 162-169.
- Becher, K., P. Vandebroek, et al. (2008). Patiënten als partners in gezondheidszorgbeleid - Meerstemmigheid in participatie: Van patiënt tot partner in beleid: mogelijkheden en hindernissen. K. Boudewijnstichting. Brussel.
- Bensing, J. (2000). "Bridging the gap. The separate worlds of evidence based medicine and patient-centered medicine." Patient Education and Counseling **39**(2000): 17-25.
- Berk, M., H. van der Steeg, et al. (2008). Stille kennis: patienten- en gehandicaptenorganisaties waardevolle bronnen van informatie. Utrecht, Julius Centrum voor Gezondheidswetenschappen en Eerstelijns geneeskunde, UMC Utrecht.
- Blume, S. and G. Catshoek (2001). Articulating the patient perspective: Strategic options for research. Utrecht, De Patiëntenpraktijk.
- Branden, T., W. B. H. J. Van de Donk, et al. (2005). "Griffins or chameleons? Hybridity as a permanent and inevitable characteristic of the third sector." International Journal of Public Administration **28**(9-10): 749-765.
- Caron-Flinterman, J. F. (2005). A new voice in science. Patient participation in decision-making on biomedical research. Amsterdam, VU.
- Cavelaars, E., G. Franx, et al. (2002). Cliëntenparticipatie bij richtlijnontwikkeling, . Utrecht, trimbos instituut,.
- Cawson, A. (1986). Corporatism and Political Theory. Oxford, Basil Blackwell.
- Coleman, J. S. (1990). Foundations of Social Theory. Cambridge?massachusetts, London, The Belknap Press of Harvard University Press.
- Commissie Structuur en Financiering Gezondheidszorg (1987). Bereidheid tot verandering. Den Haag.
- de Swaan, A. (1989). Zorg en de Staat. Amsterdam, Uitgeverij Bert Bakker.
- de Wit, F., M. Mul, et al. (2008). "Leren van patienten. De spiegelbijeekomst als kwaliteitsinstrument." Medisch Contact **63**(23): 990-993.
- Dees, J. G. and B. B. Andersen (2003). "Sector-Bending: blurring lines between nonprofit and for-profit." society **40**(4): 16-.
- Epstein, S. (2008). Patient Groups and Health Movements: The Handbook of Science and Technology Studies. E. J. Hackett, O. Amsterdamska, M. Lynch and J. Wajcman. Cambridge, Massachusetts London, England, The MIT Press: p.499-539.
- Evers, A. (1995). "Part of the welfare mix: the third sector as intermediate area." Voluntas: International Journal of Voluntary and Nonprofit Organizations **6**: 159-182.
- Giddens, A. (1994). Beyond Left and Right: the future of radical politics. California, Stanford University Press.
- Gidron, B. and H. Katz (2001). "Patterns of government funding to third sector organizations as reflecting a de facto policy and their implications on the structure of the sector in Israel." International Journal of Public Administration **24** (11): 1133-1160.
- Goudriaan, G. and A. Goris (2007). Naar een volwaardige marktpositie van patiëntenorganisaties. Leiden, STG/HMF.
- Grit, K., H. van de Bovenkamp, et al. (2008). Positie van zorggebruiker in veranderend stelsel. Een quick scan van aandachtspunten en wetenschappelijke inzichten. Rotterdam, iBMG.
- Harrison, S. and M. Mort (1998). " Which Champions, Which People? Public and User Involvement in Health Care as a Technology of Legitimation." Social Policy & Administration **32**(1): 60-70.

- Helderman, J.-K. (2006). 'Besturen met rationaliteit en redelijkheid'. Orkestratie van gezondheidszorgbeleid. Besturen met rationaliteit en redelijkheid. J. K. Helderman, P. Meurs and K. Putters. Assen, Van Gorcum.
- Hirschman, A. O. (1970). Exit, Voice and Loyalty: Responses to Decline in Firms, Organizations and States. Cambridge, Massachusetts, London Harvard University Press
- Klop, R., J. v. Kammen, et al. (2004). "Patiënten doen mee bij ZonMw!" Medische Antropologie **16**(1): 5-19.
- Loon, A. J. M. v. and R. A. L. Tolboom (2005). Ontwerprapport kiesbeter.nl 2006-2007. Bilthoven, RIVM.
- Meurs, P. and T. E. D. r. van der Grinten (2005). Gemengd besturen. Besturingsvragen en trends in de gezondheidszorg. Schoonhoven, Academic Service.
- Ministry of Health Welfare and Sport (2006). The new care system in the Netherlands: durability, solidarity, choice, quality and efficiency. Den Haag.
- Muntaner, C., J. Lynch, et al. (2000). "Social Capital and the Third way in Public Health." Critical Public Health **10**(2): 107-124.
- Najam, A. (2000). "The Four-C's of Third Sector– Government Relations Cooperation, Confrontation, Complementarity, and Co-optation." Nonprofit Management and Leadership **10**(4): 375-396.
- Nederland, T. and J. W. Duyvendak (2004). De kunst van effectieve belangenbehartiging door de patiënten- en cliëntenbeweging. De praktijk Utrecht, Verwey-Jonker instituut.
- Nederland, T., J. W. Duyvendak, et al. (2003). Belangenbehartiging door de patiënten- en cliëntenbeweging De theorie. Utrecht, Verweij - Jonker instituut.
- Nutt, P. C. and R. W. Backoff (1995). "Strategy for Public and Third-Sector Organizations." Journal of Public Administration Research and Theory **5**(2): 189-211.
- Oudenampsen, D. (1999). De patiënt als burger de burger als patient burgerschap en kwaliteitsbeoordeling in de gezondheidszorg Verwey Jonker instituut. Utrecht, Universiteit Utrecht.
- Oudenampsen, D., H. Kamphuis, et al. (2008). Patiënten en Consumentenbeweging in Beeld: brancherapport 2007 de categoriale organisaties. Utrecht, Verwey- Jonker instituut.
- Oudenampsen, D., T. Nederland, et al. (2007). Patiënten- en Consumentenbeweging in Beeld: brancherapport 2006. Utrecht, Verwey Jonker Instituut, Prismant.
- Pestoff, V. A. (1992). "Third sector and co-operative services, an alternative to privatization." Journal of Consumer Policy **15**: 21-45.
- Putnam, R. D. (2000). Bowling Alone: The Collapse and Revival of American Community. New York, London, Toronto, Sydney, Simon & Schuster Paperbacks.
- Putters, K. (2006). Het zoekende ziekenhuis: strategiebepaling in een hybride context. Meervoudig Bestuur: publieke dienstverlening door hybride organisaties. T. Brandsen, W. B. H. J. Van de Donk and P. Kenis. Den Haag, Lemma.
- Putters, K., E. Den Breejen, et al. (2008). Towards Patient Centered Governance. Rotterdam, iBMG/ErasmusMc.
- Rijkschroeff, R. A. L. (1989). Ondersteuning van participatie in de geestelijke gezondheidszorg. Amsterdam, Universiteit van Amsterdam.
- Salamon, L. M. (1995). Partners in Public Service: Government- Nonprofit Relations in the Modern Welfare State. Baltimore, John Hopkins University Press.
- Seesing, F. M., S. F. M. M. Janssen, et al. (2006). "Samen naar de dokter: Groepsgewijs consult lijkt goed alternatief voor individueel spreekuur." Medisch Contact **61**(26): 1080-1082.
- Smit, C. (2005). Overzicht van het gebruik van het patiëntenperspectief als instrument bij onderzoek.
- Taylor, J. A. and E. Burt (2001). "NOT-FOR-PROFITS IN THE DEMOCRATIC POLITY." Communications of the ACM **44**(1): 58-62.
- Taylor, M. and A. Bassi (1998). "Unpacking the State: The Implications for the Third Sector of Changing Relationships Between National and Local Government." Voluntas: International Journal of Voluntary and Nonprofit Organizations **09**(2): 113-136.

- Trappenburg, M. (2008). Genoeg is genoeg. Over gezondheidszorg en democratie. Amsterdam, Amsterdam University Press.
- van de Bovenkamp, H. M., K. Grit, et al. (2008). Zaakwaarnemers van de patient Rotterdam, iBMG.
- Van de Donk, W. B. H. J. (2001). De gedragen gemeenschap, Universiteit Tilburg.
- van Hooff, D. and I. Bochart (2007). "Meer dan een vragenlijstje. Ziekenhuis betreft patiëntervaringen bij verbetering zorgverlening." Medisch Contact **62**(37): 1508-1511.
- Van Montfort, C. and M. Oude Vrielink- Van Heffen (2006). "Bestuurskunde over zelfregulering." Bestuurskunde **4**: 2-6.
- Veenendaal van, H., G. C. Franx, et al. (2004). Patiëntenparticipatie in richtlijnontwikkeling. Evidence-based richtlijnontwikkeling. Een leidraad voor de praktijk. J. J. E. E. e. al. Houten, Bohn Stafleu Van Loghum.
- Verkaar, E. (1991). Strategisch gedrag van kategoriale patientenorganisaties. Rotterdam, EUR.
- Vossen, C. (2006). Handboek Patiëntenparticipatie in wetenschappelijk onderzoek. Den Haag, ZonMw.
- Warren, M. E. (2003). "The political role of nonprofits in a democracy." Society **40**(4): 46-51.
- Williamson, P. J. (1989). Corporatism in Perspective: an introductory guide to corporatist theory. London, SAGE Publications.
- WRR (2004). Bewijzen van goede dienstverlening. Amsterdam, WRR.
www.cbo.nl.
www.clientenbond.nl.
www.npcf.nl.
www.zorgbelang-nederland.nl.
- Zijderveld, A. C. (1999). The Waning of the Welfare State: The End of Comprehensive State Succor. New Brunswick London, Transaction Publishers.