

THE LIMITS OF PATIENT POWER

EXAMINING ACTIVE CITIZENSHIP IN DUTCH HEALTH CARE

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The Limits of Patient Power: Examining active citizenship in Dutch health care
Dissertation Erasmus University Rotterdam, The Netherlands

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ISBN: 978-90-8559-072-9

Designed by Marieke Eijt, www.me-go.nl

Printed by Optima Grafische Communicatie, Rotterdam

The Limits of Patient Power

Examining active citizenship in Dutch health care

De beperkte macht van patiënten

Een studie naar actief burgerschap in de Nederlandse gezondheidszorg

Proefschrift

ter verkrijging van de graad van doctor aan de Erasmus Universiteit Rotterdam
op gezag van de rector magnificus Prof. dr. H.G. Schmidt
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op
donderdag 4 november 2010 om 15.30 uur

door

Hester Marion van de Bovenkamp

geboren te Ede



Promotiecommissie

Promotor: Prof. dr. M. J. Trappenburg

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CHAPTER ONE

ACTIVE CITIZENSHIP AND ACTIVE PATIENTSHIP

I want to make sure that patients and clients become a strong party in health care. An equal party, next to health care providers and insurers. That means that patients and clients should be able to choose what care is best for them, that they should be able to influence the care they receive and that they should feel safe and understood (Ab Klink, Dutch minister of Health, Welfare and Sport. Speech, 30 October 2008).

We have to make sure that they [patients] really and justifiably feel safe with us and are informed adequately and on time. Of course, we have ideas about how we can improve our service, but it would be great to work out these improvements in dialogue with the patient (Hans Büller, chairman of the board of directors, Erasmusmc, www.erasmusmc.nl).

Patients and consumers are 'customers' and experiential experts. They have an opinion on what 'good care' is. The NPCF [National Patient and Consumer Federation] tries to make this opinion central in the assessment of the quality and efficacy of care (www.npcf.nl).

Introduction

These quotes make it evident that the Dutch minister of health, health care providers and patient organisations all believe that patients should have more say in health care and to accomplish this they should be given an active role in decision-making. The quotes also show that patients should be the equals of health care providers and insurers, since they are entitled to good health care and have the knowledge and expertise to determine what good quality care is. The views expressed by Dutch health care actors echo similar views expressed by health care policy-makers in other Western countries. Modern health care policy is directed at giving patients an active role in health care instead of keeping them the passive recipients of care they used to be. According to the British economist and policy advisor Julien Le Grand, patients should turn from 'pawns into queens' (Le Grand 2003). They should become active participants in health care decision-making, making informed choices of health care providers, getting involved in shared decision-making with medical professionals, and participate in client councils and patient organisations. Much is expected from this policy. Presumably it will both democratise decision-making and increase the effectiveness of health care. Much time, money and energy have been spent on this type of health care reform. Policy-makers seem to think that if patients are provided with information and the opportunity to participate, the benefits of the reform will surely follow. However, it is still unclear if this policy of active patientship is actually working in practice and that makes it important to learn more about it, to find out whether patients really can play an active role, to establish whether the supposed benefits really occur and if there are any unintended side-effects or consequences of the policy. This thesis addresses these issues.

The thesis focuses on the Netherlands since this is one of the countries that have gone furthest in giving patients an active role in health care decision-making (Rice, Biles et al. 2000; Grit, Van de Bovenkamp et al. 2008). Dutch patients are dubbed the official *third party* in health care, beside health care providers and insurers (TK 16771 no.2, 29214 no. 24). As similar trends can be seen in other countries (Evans 2000; Morone 2000; Rice, Biles et al. 2000; Lofgren 2004; Evans 2005; Clarke, Newman et al. 2007; Leys, Reyntens et al. 2007; Newman and Kuhlmann 2007; Bagott and Forster 2008; Jones 2008), the Dutch case seems interesting for an international audience as well.

This chapter contains a general introduction to the topic of active patientship. First it takes a step back to explore the broader policy trend of active citizenship, which includes active patientship. After this the focus is on the health care sector. The chapter also describes the aim, research question and various parts of the study and ends with an overview of the remaining chapters.

Active citizenship

Changes in the role of patients in health care are substantive and receive a lot of attention from researchers in this particular policy field. However, it is important to note that they do not stand alone but are part of similar trends in other policy sectors. A more active role and more responsibilities are expected of citizens in all kinds of policy sectors. Active citizenship is an important policy focus in many Western countries (Tonkens 2006; Clarke, Newman et al. 2007; Trappenburg 2009). One of the roots of this policy focus is the idea that the existing organisation of the welfare state makes people dependent, passive and lazy and therefore reforms are necessary to activate citizens. These ideas can be traced back to the neo-liberal idea of 'rolling back the state' exemplified by the Thatcher and Reagan governments (Held 2006), but similar ideas can also be seen in other governments and other countries. In the active citizenship debate emphasis is laid on both citizen's rights and responsibilities. It claims that citizens have the right to make decisions which concern their own lives, but also that they ought to take responsibility for themselves, for each other, and for the society to which they belong.

Citizens are thus expected to become active in three ways: they should take care of themselves, they should take care of each other and they should be active in the organisation of public policy and services in general.

Taking care of themselves comprises two aspects. First, citizens should not rely passively on the state for the solution to their problems but should be self-reliant and try to solve their problems themselves. Think of the 'workfare' emphasis laid on people re-entering the labour market rather than receiving government benefits (Esping-Andersen 1996; Rob 2004; Tonkens 2006). In addition citizens should play

an active role with regard to the use of public services. People are expected to formulate their needs and inform themselves about the quality of services and choose the provider that suits them best, be it a municipality, a school or a day care centre (Hurenkamp and Kremer 2005; Clarke, Newman et al. 2007).

Secondly, citizens are expected to take care of each other. As in the self-help philosophy, people should first take care of each other before turning to the state for help. If they helped one another, this may preclude the necessity for state help, whereby the burden shifts away from state resources toward individuals and communities. Citizens are therefore called upon to help people in their social network and do volunteer work (Tonkens 2006).

Thirdly, citizens are expected to carry out activities to improve public policy and services in general. Citizens can participate in decision-making on subjects such as urban renewal plans, policy agenda and priority setting and social housing. This third category includes citizen participation through citizen forums and deliberation days (Beukenholdt-ter Mors, Daemen et al. 2002; Rob 2004; Clarke, Newman et al. 2007; Paddison, Docherty et al. 2008). Regarding this third form of participation it is important to realise that it is not restricted to individuals, a large portion is attributed to civil society organisations. Thus, the activities of citizens in this realm can take place on two levels; the individual and the collective level. Citizens may actively partake as individuals in the development of policy agendas. However, they may also choose to unite in civil society organisations, which have an important role in decision-making processes because they try to influence policy-making for certain groups. Examples are organisations, such as unions, environmental groups and human rights groups. These groups can influence collective decision-making and try to change policy and public services in general.

The next section explores the reasons behind the turn toward active citizenship. Two sets of arguments seem to support the case for active citizenship. On the one hand active citizenship is supposed to democratise decision-making (first set of arguments) and on the other hand it is supposed to make decision-making and public service provision more effective (second set of arguments). Both sets of arguments are described in turn.

Democratisation

From the perspective of democratisation citizens have certain rights and responsibilities which require them to become active. First, it is argued that people have the right to have a say in decisions concerning their lives. Exerting this right makes decisions more legitimate since it gives the people the opportunity to influence the decisions that affect them. This line of reasoning calls especially on the influence of citizens through the use of voice (Hirschman 1970). Citizens have to be able to ex-

press their opinion on certain matters and thus influence decision-making.

There have been different ideas about democracy throughout history. The debate on the importance of democratic decision-making dates back to ancient Greece where the free male citizens of Athens came together to decide on matters concerning the state. Centuries later, when interest in the importance of democratic decision-making was rekindled, it was felt that this type of direct democracy was no longer feasible and as a result representative democracy was introduced. People could vote for a representative who would make decisions in their name (Held 2006). However, recent decades have seen expressions of growing discontent with this system and it has been argued that citizens should have more opportunities to participate. The idea of the importance of participation in decision-making besides voting in elections gained strength in the 1960s and 1970s in the Western world. Representative democracy was deemed not democratic enough; it put people under the rule of a middle-aged male elite. The democratisation movement established in this period successfully tried to increase the possibilities for citizens to voice opinions on certain matters (Hurenkamp and Kremer 2005; Hendriks 2006; Trappenburg 2008). All kinds of participatory and deliberative decision-making processes have been introduced since, to enable people to express their voice (Beukenholdt-ter Mors, Daemen et al. 2002; Held 2006; Hendriks 2006; Roberts 2008). Introducing such possibilities stems from the idea that increasing participation possibilities of citizens will make decision-making more democratic, since it raises equality by enabling people to influence decisions concerning their lives instead of being dependent on others.

Democratic decision-making gives citizens the opportunity to influence decision-making. In addition, however, democratic thinkers like Rousseau and Mill have long pointed out that participation in democracy is a civic virtue and a means to moral self-development. This view was also held by the ancient Greeks who saw participation as a civic duty and who frowned upon those who did not participate as useless citizens (Held 2006). The active role of citizens is therefore also important in this regard. Citizens not only have a right to participate, but also a moral duty to participate and their participation serves an emancipatory purpose.

As stated above, individual citizens can participate in decision-making processes but they can also unite in civil society organisations which set out to influence decision-making on their behalf. Civil society organisations are considered important for democracy for several reasons. First, such organisations provide an avenue for citizens to let their voice be heard (Evers 1995; Backman and Smith 2000; Warren 2003).¹ They give citizens the chance to influence decision-making through lobbying or participation in formal decision-making procedures. Secondly, it is frequently argued that civil society organisations foster social capital, social skills and public virtues such as solidarity, trust, toleration and concern (Evers 1995; Zijderveld 1999;

Backman and Smith 2000; Putnam 2000; Van de Donk 2001; Ilcan and Basok 2004).

Increasing effectiveness

Besides the argument that it is important to activate citizens for democratic reasons, it is argued that active citizens contribute to effective policy-making and service delivery.²

From the 1980s onwards it was felt that existing welfare states needed to be reformed. They had become too expensive, jeopardising the economic position of countries. Furthermore, welfare states were established in a period when equality was considered important and services were directed at a relatively large working class with fairly homogenous preferences, which did not fit the new social order. Today there is far more diversity, welfare state services must take into account far more heterogeneous needs and expectations (Esping-Andersen 1996). In this line of argumentation, heterogeneity is linked to increased individualisation of society (Esping-Andersen 1996; Schnabel 1999). Preferences have become more diverse as a result of individualisation and providers should respond to this. Moreover, the higher level of prosperity and increased supply of available information have raised people's expectations and standards whilst simultaneously allowing them to play a more active role (De Swaan 1989; Schnabel 1999). This also demands public services that are more responsive to individuals.

Thus arose the proposals for reforms that are supposed to increase the effectiveness of the system, including activating citizens as an important element. First, public spending could be reduced by calling upon citizens to take initial responsibility for solving certain problems either by themselves or in their social network before turning to the government for help. Second, policy and services could be tailor-made to suit the individual by tapping into citizen preferences in policy-making and service provision. Thus the public services provided would become far more directed at individual citizens. Citizens would play an active role, which would give

¹ However, their democratic role is subject of debate since they are not formally legitimised to play a role in public decision-making (Van der Grinten 2006). Notably, despite the fact that they try to encourage more citizens to voice their opinions, nonetheless they reproduce simultaneously a top-down structure where citizens are still spoken for by others. Arguably they represent the interests of certain groups only at the cost of less well-organized groups and can thereby diminish the representative democratic system (Van den Berg and Molleman 1975; Coxall 2001; Held 2006).

² Although one of the arguments for democratic decision-making is also that it will lead to the best outcome, this line of reasoning is discussed separately here since the idea that active citizens will lead to more effective policy-making does not stem from democratic thought alone but also draws from other backgrounds.

them more control (Ilcan and Basok 2004; Clarke 2006). During the 1980s and 1990s many governments of advanced industrial countries championed market-oriented reforms to the welfare state, accommodating the shift toward individualisation and more active participation (Smith 2002; Helderma 2007). Some public services were privatised (Esping-Andersen 1996). Others were reorganised and steering mechanisms from the private sector were introduced with the advent of New Public Management (Rosenthal, Ringeling et al. 1996). The idea behind this was that organising public services like markets would make them more efficient. The activities of citizens are important here because this type of organisation asks them to behave like critical consumers. Besides using the mechanism of voice to express their preferences and represent their interests, now they must also use the mechanism of exit and choice (Hirschman 1970): inform themselves about options, choose the one that suits their individual needs best and when dissatisfied with a certain service leave it for the competition. The idea is that exit and choice behaviour will force providers to compete with each other and improve the quality and efficiency of their work. Besides enabling more citizen-centred service provision, the consumer role of citizens is therefore also expected to raise the quality and efficiency of services in general.

Although there is this strong focus on the activities of individual citizens, collective activities of citizens remain important as well since civil society organisations can also help improve the effectiveness of public services. Participation of citizens or their organisations on the meso and macro levels can provide important insights that can improve the quality of decision-making. It can also increase the chance of implementation since citizens have already shown their support of the decisions (Rob 2004).

Thus, the policy of active citizenship stems not only from an intrinsic value: people should be empowered to voice their opinion on certain matters that influence their lives; but also an extrinsic value: the active role of citizens will increase the effectiveness and quality of provided services and decisions. These are high expectations of both the effects of this active role and of citizens themselves since they are expected to perform all these activities.

Active patientship

Health care can be seen as a policy field where all participation possibilities accumulate and the expectations of the active role of the citizen, in this case the patient, are especially high. The Netherlands can be considered a frontrunner; attributing an active role to patients both on the individual and the collective level is an important focus of policy. The following part of this chapter is therefore focused on Dutch health care.

Health care policy in the Netherlands expects citizens to become active in the

three aspects discussed in the previous section: their own care, care for each other and the health care services in general. First, people are given increasingly more responsibility for their own health. They should avoid illnesses by taking up a healthy lifestyle and manage their own health when they do fall ill, for instance by therapy adherence. The modern patient has to critically compare the quality of care and services offered by different health care providers and insurers and choose the one that performs best according to his own individual criteria. He should discuss possible treatment options and the organisation of his care as an equal partner of his doctor. When dissatisfied with his care the patient can make complaints or leave his health care provider or insurer for the competition. He can also use a personal budget to organise part of his care, such as home care, himself.

Secondly, the expectation that citizens should take care of each other also applies to health care. The Social Support Act (*Wet maatschappelijke ondersteuning*) introduced in 2007 emphasises the importance of informal care and volunteer work. Before patients can call on the professional care system they have to try to organise care in their informal network. Therefore, the active patientship policy also affects individuals in the social network of the patient. Especially family members are expected to care for patients. So although the emphasis lies on activating the patient in health care, his social network is activated simultaneously.

Thirdly, activities of patients on the collective level also gain much attention in national policy. The Dutch case is interesting in this regard since patient organisations play a very important role. Patient organisations can actively participate in formal decision-making procedures on subjects such as health research, guideline development and local, regional and national policy-making. They have become part of the neo-corporatist decision-making structure of Dutch health care, which means they are recognised by the government and other actors in the field as legitimate discussion partners.

In Dutch health care the same distinction between active patientship from a democratic point of view and from the point of view of increased effectiveness can be made.

Democratisation of health care

The democratisation movement of the 1960s and 1970s also had its effect on health care. It was argued that patients are important stakeholders with a democratic right to have a say in decisions concerning their care. This democratisation movement was strongest in mental health care, where the anti-psychiatry movement played an important role (Trappenburg 2008). The anti-psychiatry movement wanted patients to be empowered and seen as autonomous individuals who should have an active voice in decisions concerning their care. This idea was taken up by policy-makers and

professionals; patients were indeed given more opportunities to voice their opinion on health care, not only in the context of their individual treatment but also collectively, for instance in client councils of mental health care institutions (Trappenburg 2008; Oosterhuis and Gijswijt-Hofstra 2008). This particular mode of health care democratisation stems from the specific notion of patients as citizens with certain rights to influence decision-making that thereby make decisions more legitimate. This idea of patients as citizens also resulted in a focus on introducing patient laws to strengthen the position of patients. In the Netherlands this was a subject of much debate in the 1980s and in the 1990s several patient laws were introduced³ (Van der Kraan 2006). An important notion in this legislation is that patients are autonomous individuals who should be able to make informed decisions concerning their care. This policy of active patientship is expected to empower patients and raise them to be 'good' patients who take responsibility and are in control of their own life (Adams 2006). Similarly the emphasis on activating individuals in the patient's social network to provide informal care can be regarded in terms of raising good citizens.

Besides enabling individual patients to influence their own care, many participation possibilities are created on the collective level. Policy-makers acknowledge that individual patients cannot play their active role alone; they need sponsors to support them. Patient organisations are an especially important category of sponsors (Van de Bovenkamp, Grit et al. 2008a). Patient organisations are given a third-party role by the Dutch government to act as representatives of patients in all kinds of decision-making processes. They are expected to bring an additional perspective to the table, one that draws on their experiential knowledge (Van de Bovenkamp, Grit et al. 2008b). The idea is that their experience is the basis of an additional perspective that other actors cannot put forward on their behalf. Patients therefore need to be present in decision-making to be able to put this perspective forward (cf. Phillips 1995). In this line of reasoning other actors, such as health care professionals cannot represent patients' interests, only patients themselves can do this. Since patients have a strong interest in health care decision-making which needs to be heard when decision-making is to become more democratic, it is important that they are able to participate in decision-making processes. In addition, patient organisations can also play an important role for democracy since they can offer a group of people,

³ The Netherlands has several laws pertaining to patients: the Medical Treatment Contracts Act (*WGBO*), the Psychiatric Hospitals (Compulsory Admissions) Act (*wet BOPZ*), the Client Right of Complaint Act (*WKCZ*), the Co-Determination of Health Care Institutions Act (*WMCZ*), the Quality of Health Care Institutions Act (*Kwaliteitswet zorginstellingen*), the Health Insurance Act (*Zorgverzekeringswet*) and the Social Support Act (*Wmo*). Currently in preparation is a health care consumer act, which bundles most of this legislation.

patients, who may have difficulty finding it elsewhere because of their condition, a place to increase their social capital (Trappenburg 2008). Participating in health care decision-making is therefore expected to have an empowerment effect on those who participate. It could also contribute to a cultural change in health care towards a more equal position of patients (Van de Bovenkamp, Grit et al. 2008b).

Increasing effectiveness of health care

The importance of democratising health care by giving a voice to patients has not left the Dutch policy agenda, but has been combined with a more economic perspective to activating patients. As in general welfare state policy, policy in the health care sector is putting forward the idea that self reliance, empowerment and taking care of each other, can reduce public spending. Patient participation is also expected to increase the quality of decisions and the effectiveness of the health care system (Van der Kraan 2006).

In the 1980s a more economic view to health care was put forward in the Netherlands, in line with the general policy trend. Health care should function more as a market to become more effective. The patient should act as a critical health care consumer. This would result in care that would be more attuned to individual patient preferences and in a more efficient health care system. In the Netherlands the Dekker committee recommended such a policy reform in 1987. It remained on the policy agenda through the years, and after many incremental steps a system of regulated competition was introduced with the Health Insurance Act in 2006 (Helderman, Schut et al. 2005). This act introduced a system in which: 'the patient – the insured party – truly occupies centre stage' (Ministry of Health, Welfare and Sport 2006).

In this new policy patients are expected to act as an equal party to health care providers and insurers. The active role of individual patients is important here, but so are the activities of patient organisations. Participation on the individual level enables health care services to become more attuned to individual patient preferences and can therefore provide better health care to individual patients. Participation on the collective level will bring to the table the patient perspective as an addition to those of providers, insurers, researchers and policy-makers (Caron-Flinterman 2005; Van de Bovenkamp, Grit et al. 2008b). This is expected to improve the quality of decisions. The experience of patients living with a certain condition and their experience with the health care system can offer important subjects for improvement (Blume and Catshoek 2001). It is also claimed that the chance of decisions being implemented will increase since through their organisations patients are already committed to these (Van Veenendaal, Franx et al. 2004).

Participation in health care from various perspectives

We can conclude several things from the description of policy directed at patients. The most obvious conclusion is that these are busy times to be a patient. You do not get to focus just on being sick, getting better or trying to cope, things that already cost an enormous investment of time and energy. Especially considering the facts that people are increasingly expected to keep on working, that hospital stays are shorter and that people are asked to be as self-reliant as possible (Trappenburg 2008). In the past this was easier. According to the sick role described by Parsons (1951) patients were excused from their normal role in society and were not considered responsible for their illness. They only had to focus on getting well and cooperate with medical professionals. This has now changed, as the patient is currently expected to play an active role in improving the quality of his own as well as other people's health and care.

Another related conclusion is that the concept of patient and the ideas behind it have changed considerably. Now a patient is an autonomous individual with certain rights and responsibilities instead of the passive recipient of care. This policy requires many activities and responsibilities from patients and carers. Patients have to inform themselves and make important decisions on the basis of this information on both the individual and collective level. Patients and carers not only have the right, they also have the responsibility to do so. A shift in responsibility from the government and health care professionals towards patients and carers is therefore an important part of this policy change (Swierstra and Tonkens 2005).

A third conclusion is that patients are offered the possibility to participate on all kinds of subjects and levels. This means that the other actors in the health care field are all trying to involve the patient, showing that it has become a widely accepted phenomenon. Furthermore, policy-makers are trying to kill two birds with one stone as the policy is expected to make decision-making simultaneously more democratic and more effective. The debate on patient participation has formulated both ideological and practical arguments for this development: it is the right thing to do and it will lead to better decision-making. Both ideas have become strongly embedded in the Dutch health care system.

Criticism

The policy of attributing an active role to patients is not free of criticism. Critics question the individual's willingness to choose and raise their voice (Tonkens and Swierstra 2002; Hurenkamp and Kremer 2005; Trappenburg 2005; Clarke, Newman et al. 2007). Others point out that market mechanisms will not work in health care and will only decrease the quality of care that is provided (Mol 2006). Another criticism is that the policy could lead to differences in the quality of care provided to different

groups. The active role of the patient could be empowering for individuals but this is also a difficult role to perform. Acting autonomously puts high demands on people (Stüssgen 1997). The danger is that it will lead to differences in the quality of care provided to the people who can perform this role and those who cannot. Those who can are most likely already well-off people: young and highly educated. Those who cannot are already more vulnerable: the lower educated, the elderly and people with for instance a mental or psychiatric disability (Grit, Van de Bovenkamp et al. 2008). Emphasising individual responsibility could also undermine the solidarity of the system, since not receiving the best quality care, or even becoming sick in the first place, becomes your own fault (Hurenkamp and Kremer 2005, Mol 2006). Another danger is that those who raise their voices and demand the best and fastest care will be rewarded while those who sit quietly will have to wait and might get lesser quality care. Such a system would not raise 'good' empowered citizens but 'rude' citizens instead (Trappenburg 2008).

The critics question both goals behind participation. That it will lead to inequality between groups who can and those who cannot participate undermines one of the central values of democratic decision-making (Held 2006). That this policy would undermine quality of care and that few people use opportunities to participate, also questions the expectation that it will improve the effectiveness of health care. The question is if this limited use and the difficulty patients have in fulfilling their active role is based on practical considerations or something more fundamental. Research is showing that the critics seem to be right in their evaluation of people's willingness to become active. Individual patients make little use of their choice or voices options (Dorgelo, Hekkink et al. 2008; Grit, Van de Bovenkamp et al. 2008). Some argue that it will just be a matter of time and then people will behave according to the policy ideal, once they get the right information or have become more accustomed to the idea, for instance (Groenewoud 2008). The same goes for participation on the collective level. Patient organisations are not an equal party yet but researchers argue that they can be when given proper support and improved participation methods (Van Veenendaal, Franx et al. 2004; Goudriaan and Goris 2007; Berk, Van der Steeg et al. 2008). However much of the criticism on the strong focus on patient participation in health care cuts deeper. Critics argue that some groups will never attain the policy ideal and will suffer negative consequences as a result. Forcing people to act as critical consumers will lead to undermining of the solidarity of the health care system and to the erosion of trust, an important part of the physician-patient relationship.

This study

Policy-makers have high expectations of giving patients an active role and their policy is directed at creating these conditions in practice. All parties in the health care

field are promoting participation, at least by lip service (Van de Bovenkamp, Grit et al. 2008a). However, there is also fundamental criticism of this policy and what its actual effect will be is still largely unknown. How the policy-makers think this policy should work has been described above. Whether it really will work like this remains largely an open question. Therefore it is important to learn more about what is happening to participation in practice, before adding further to participation opportunities. This thesis contributes to this knowledge.

Research aim and question

The thesis focuses on the policy of active patientship on the individual and the collective level, on how the different goals and ideas are combined and what the effects of this policy can be. The central research question is:

What experience has been gained in implementing active patientship policy? Are its goals being achieved in practice and can patients take on the active role expected of them?

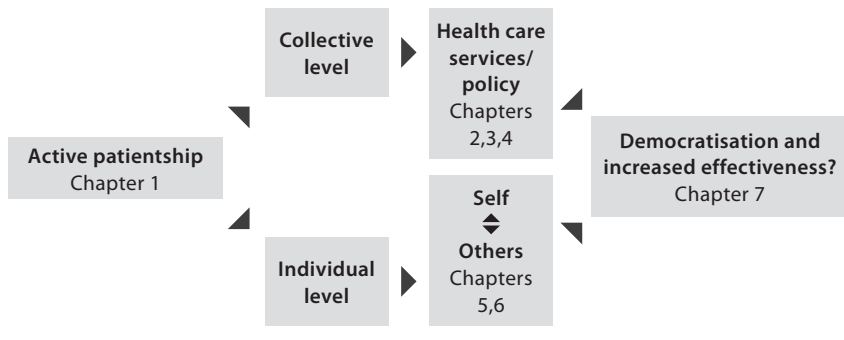
To answer this question, this thesis examines several cases of active patientship and their consequences. The first part studies participation on the collective level, focusing on the role of patient organisations. This focus is chosen because it is an important aspect of active patientship in the Netherlands while the results remain largely unclear. Patient organisations have become part of the neo-corporatist decision-making structure in health care and it will be interesting to see what the effects of this are in practice.

The second part of the thesis examines the consequences of active patientship policy on the individual level, focusing on mental health care. This is an interesting sector to study the effects as this sector has the longest history of regarding the patient as an autonomous individual who should have the right to influence decisions concerning his care. The mental health care sector also offers important insights into the combination of different aspects of active citizenship, since it combines a strong focus on patient autonomy with the emphasis on informal care by family members.

The following section describes the various parts of the study, including the chapters, in more detail. A schematic overview of the outline of the thesis is given in Figure 1.

Participation on the collective level

Chapters 2 to 4 focus on patient participation on the collective level. Chapter 2 looks in depth at guideline development, where patient participation is proposed and

Figure 1 Schematic overview of thesis

put into practice. Many Western countries are introducing opportunities for patient participation in decision-making on government policy, provider policy, medical research and medical guideline development (Crawford 2002; Caron-Flinterman 2005; Trappenburg 2008; Van de Bovenkamp, Grit et al. 2008b). However, little seems to be known about its effects. This chapter offers insights into the effects, using guideline development as a case study. After a systematic review of the international literature on this subject it is concluded that there is very thin evidence that patient participation is delivering the desired results of more effective and democratic decision-making. It is further concluded that participation in such a process is difficult and can even contradict the policy goal of providing more patient-centred care.

Chapter 3 focuses on Dutch government policy directed at patient organisations. Countries differ in the extent of possibilities for patients or their representatives to participate in decision-making and in the way they put this into practice. In the Netherlands many possibilities are created for participation on the collective level. There is a strong focus on the involvement of patient representatives in formal decision-making bodies, which fits the Dutch practice of neo-corporatist decision-making. Health care has never been a policy field in which government decided on the policy course on its own. Because of the hybridism of the health care system the government has always depended on societal organisations (health care providers, professionals, insurers). Consultation in the field has therefore always been important (Van der Grinten 2006; Bal 2008). Although with the introduction of the system of regulated competition this consultation is no longer obligatory in health care, it does still happen (Bal 2008). What is relatively new is the participation of patients. Since the 1980s patient organisations have been recognised by the Dutch government as an important stakeholder. The government put forward the idea that patient organisations should be involved in health care decision-making by providers and insurers and in their own policy-making as well (TK 16671 no.2, 22702 no.2,

27807 no. 22). According to the policy documents patient organisations should become the 'third party' in health care decision-making beside providers and insurers. The government created the circumstances through for instance giving them seats in official advisory bodies, and also by subsidising patient organisations and attaching criteria to these subsidies (Trappenburg 2008). Chapter 3 compares these policy ideas to the actions of patient organisations to see what the effects of this policy have been. On the basis of a document analysis it is concluded that government influence on patient organisations is quite strong thus enabling patient organisations to become part of all kinds of formal decision-making procedures. Governmental influence, however, has also steered their course of action. From the perspective of government this can be seen as effective policy-making. From the perspective of patient organisations the situation can be valued positively at first sight as well, but looking more closely there are also disadvantages. This situation raises questions about how much government influence on civil society is acceptable from a democratic point of view.

Chapter 4 looks at the practice of patient organisation participation in the Dutch neo-corporatist decision-making structure. This chapter analyses whether this is a good model of patient participation on the basis of interviews. Research into the practice of participation of patient organisations is scarce. The existing research does show that patient organisations perform many activities (Berk, Van der Steeg et al. 2008; Oudenampsen, Kamphuis et al. 2008; Trappenburg 2008). What all this participation accomplishes and how it works out in practice remains largely unclear, although there are indications that patient organisations find it difficult to fulfil this active role (Trappenburg 2008). Chapter 4 concludes that patient participation in a neo-corporatist decision-making structure raises additional problems to the problems generally identified with such a structure. It does not necessarily lead to more effective and democratic decision-making.

Participation on the individual level: the case of mental health care

Chapters 5 and 6 focus on the effects of the policy of active patientship on the individual level and on how this policy works when combined with the policy of activating citizens to care for each other: provide informal care to sick family members. To study active patientship on the individual level the focus is on mental health care, since, due to its history, this sector has the longest relevant experience. It is therefore possible to study the long-term effect of this policy in this sector. The anti-psychiatry movement, consisting of mental health workers and patients, was very successful in the 1960s and 1970s in changing policy in mental health care to make it more democratic. Instead of patients or clients being passive recipients of care they had to be seen as autonomous individuals who could make decisions for themselves

(Oosterhuis and Gijswijt-Hofstra 2008). In other sectors of care the strong focus on active patientship is more recent. It is interesting to look at mental health care to learn about the consequences since they can provide important insights from which other health care sectors can learn.

Chapter 5 focuses on the practice of mental health care and the relationship of professional care workers and informal carers (family members). Because of the frontrunner position of mental health care, the debate about and research into the practice and consequences of this policy have also developed further (cf. Anstadt 1983; Pols 2004; Crossley 2006; Oosterhuis and Gijswijt-Hofstra 2008). This policy with its strong focus on patient autonomy has been heavily criticized. Some critics even speak of a failure of democratisation since it has resulted in patient neglect (Stockman 2000; Oosterhuis and Gijswijt-Hofstra 2008). Many patients could not fulfil the high standard of autonomy, independence, emancipation and self-development (Oosterhuis and Gijswijt-Hofstra 2008). Pols shows that a strong focus on the autonomy of mental health care patients leads to a situation in which other important values such as solidarity and social relationships are ignored, which can lead to neglect and loneliness (Pols 2004). Family members of patients and their organisations played an important role in the identification of these problems (Oosterhuis and Gijswijt-Hofstra 2008). As a result, their own role in the care process became complicated. On the one hand family members were seen as an important cause of mental illness (especially mothers) in the anti-psychiatry tradition. On the other hand the policy of deinstitutionalisation, which took off in the 1990s, forced them to take care of their sick relative since they would otherwise have suffered neglect. The carer role was perceived as a heavy burden (*ibid.*). The effects of this policy on family members have therefore been identified as an important subject, which requires more research (*ibid.*). This case is also interesting since here the different aspects of active citizenship in health care come together: taking care of oneself and taking care of one another. This chapter thus studies the role of family members in mental health care. It shows that a strong focus on the patient as an autonomous individual not only has negative consequences for his family but also on the quality of care provided, because family members have been excluded from the formal care process. This situation shows that the policy cannot be regarded as effective since it has negative consequences for both patients and family members. From a democratic point of view the important question is who is allowed to participate. That there is a strong focus on the patient only while other stakeholders are excluded is undesirable from the democratic perspective.

Chapter 6 compares these findings to other sectors of health care. The role of family members is also interesting in light of the broader debate on active citizenship which expects a more active role of the patient's social network to care for their

loved one (Tonkens, Van den Broeke et al. 2008). This information is not only important to contribute to the mental health care debate but can also offer more insight in possible consequences of the active patientship policy in general. Therefore this chapter investigates whether the findings in mental health care can be generalised to other care sectors by drawing comparisons with nursing home and oncology care. On the basis of the findings it is concluded that the situation in mental health care cannot (yet) be generalised to other sectors. For care quality, it is important to involve family members in mental health care, while attention should be paid to the possibility of the undesirable effect of a strong focus on patient autonomy and individual interests on family members in other sectors.

The broad policy of active patientship

Chapter 7 draws overall conclusions from the data presented in this study, returns to the central research question and raises points for discussion. It concludes that the goals of effective health care and more democratic decision-making cannot be unambiguously found in practice. It shows that the different goals do not necessarily coincide. These results lead to the conclusion that there are and should be limits to patient power.

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CHAPTER TWO

RECONSIDERING PATIENT PARTICIPATION IN GUIDELINE DEVELOPMENT

This chapter was published as:

Van de Bovenkamp H.M., M.J. Trappenburg (2009). Reconsidering Patient Participation in Guideline Development. *Health Care Analysis*, 17 (3): 198-216

Introduction

Patient-centred medicine is one of the dominant paradigms if not the dominant paradigm in modern health care systems. It focuses on patient participation at different levels of decision-making. The paradigm is strongest in individual physician-patient contacts, in which ample attention is paid to the individual patient's point of view and to his or her needs and preferences (Bensing 2000). It is assumed that patients and doctors engage in a process of shared decision-making. For example, patients must be given all the information they need in order to choose between treatment A and treatment B. Physicians should help patients in making these decisions. Arguments in favour of patient-centred medicine are mainly principle-based since patient autonomy is considered a basic value, but they also have a practical side; patient-centred medicine is assumed to improve adherence to treatment recommendations (Grol 2001). According to Salmon and Hall the scientific basis for the importance of choice and control is weak. They argue that the discourse of patient empowerment became so strong partly because it offers clinicians a perfect way to withdraw from areas of patient need that are problematic for them, such as unexplained symptoms, chronic disease, and pain. Responsibility for these complicated forms of illness is gladly transferred to the empowered patient (Salmon and Hall 2003, 2004). Still even these sceptical authors, who do not applaud the recent developments, acknowledge that patient-centeredness has become a dominant paradigm in modern medicine.

The individual physician-patient level is not the only level of decision-making in health care that is becoming more patient-centred. Increasingly, patient representatives, in the Netherlands often volunteers of patient organisations, are asked to participate in decision-making at the macro level. They can voice their opinion on the medical research agenda (Caron-Flinterman 2005), evaluate health care laws and advise on national policy (Trappenburg 2008) and contribute to medical guideline development. In this chapter we will focus on the latter. In the Netherlands, as in other countries, patient participation in guideline development is becoming increasingly common. It was encouraged by the Dutch government in 1995 (TK24126 no.9). In 2000, the Dutch Health Council, an important domestic advisory body, proposed patient participation in the development of guidelines (Gezondheidsraad 2000). Since then, organisations charged with guideline production in the Netherlands have been trying to actively involve patients in the guideline development process (Van Veenendaal, Franx et al. 2004; www.cbo.nl; www.trimbos.nl). Earlier, this democratic approach had been adopted by countries such as Australia and the United Kingdom and it is also found in other countries (Graham, Beardall et al. 2003; Rankin, Newell et al. 2000; Schunemann, Fretheim et al. 2006; Van Wersch and Eccles 2001).

One of the items on the AGREE (Appraisal of Guideline Research and Evaluation) instrument, a European checklist to assess the quality of professional guidelines,

stipulates that a high quality guideline should take patients' preferences into account (AGREE Collaboration 2001). But how should this be done? In this chapter we present a review of the literature search we performed on patient participation in guideline development with a view to answering the following question: *What is the current state of the debate and the current state of affairs regarding patient participation in guideline development?* After the Methods section, we first describe the studies we found and the arguments identified in the literature on this subject. Subsequently, we concentrate on the studies that report on patient participation in guideline development practice. In the Discussion we argue, on the basis of the literature, that increasing active patient participation in guideline development is not as logical a step towards patient-centred medicine as it may seem.

Methods

To answer the research question we performed a literature search in Pubmed/Medline, the Cochrane Library, Web of Science and the online contents on the subject of patient participation in guideline development. The keywords used were: patient participation guideline development (84 hits), consumer participation guideline development (117 hits), patient involvement guideline development (103 hits) and consumer involvement guideline development (121 hits). Out of a total of 425, 86 hits seemed relevant to our research question on the basis of title and abstract (double hits excluded), but after closer inspection only 20 articles remained. Regrettably, we had to exclude studies and letters not written in either English or Dutch. We also excluded studies that did not refer to patient participation in guideline development in any way. We found additional publications by means of the chain referral technique, i.e., by also examining the lists of references of the studies selected. In addition, in the 'grey' literature including (commissioned) research, advisory and experiential reports, we found evaluations and other research reports on patient participation in guideline development. After close scrutiny of these publications, we selected 22 studies thus bringing the total to 42.

The main, or very important focus, of 20 of the studies we selected was patient participation in guideline development. Three studies dealt with patient participation in decision-making processes in general, including guideline development. Seventeen articles dealt with guideline development processes in general, including patient participation. The last two publications were reflections on evidence-based practice and other popular concepts in health care in which guidelines, and patient participation in guideline development, was one of the subjects discussed. An overview of these articles is presented in Table 1. We performed a content analysis on these articles which resulted in a preliminary analytical scheme after six articles, which was refined after analysing the other studies. The definitive analysis scheme

consisted of the following subjects: (1) the nature of the study (empirical or not) (2) the focus of the article (was patient participation the main focus of the article), (3) the kind of guideline that was studied, (4) the arguments used for participation, (5) the participation methods, (6) the difficulties encountered, (7) the added value of participation and (8) the recommendations for the future.

Table 1 Studies on patient participation in guideline development

| Main or very important focus | Not main focus | |
|--|---|-----------------------------|
| Nease and Owens (1994) [1] | <i>Articles on patient participation in decision-making</i> | |
| Bastian (1996) [2] | | |
| Duff et al. (1996) [3] | | |
| Butow et al. (1996) [4] | Williamson (1998) [21] | |
| Schofield et al. (1997) [5] | Crawford et al. (2002) [22] | |
| Owens (1998) [6] | Nilsen et al. (2006) [23] | |
| Bauchner and Simpson (1998) [7] | <i>Articles on guideline development in general</i> | |
| Saltman (1998) [8] | | |
| Lanza (2000) [9] | | |
| Rankin et al. (2000) [10] | | |
| Van Wersch and Eccles (2001) [11] | | |
| Kelson (2001) [12] | | |
| Rogers (2002) [13] | | |
| Cavelaars et al. (2002) [14] | | |
| Jarret et al. (2004) [15] | | |
| Van Veenendaal et al. (2004) [16] | | |
| Goossensen et al. (2005) [17] | | |
| Van Wersch and Van den Akker (2005) [18] | | |
| Schunemann et al. (2006) [19] | | |
| Sieders (2006) [20] | | |
| | | Field and Lohr (1992) [24] |
| | | Gilmore (1993) [25] |
| | Carter et al. (1995) [26] | |
| | Grilli et al. (1996) [27] | |
| | Eccles et al. (1996) [28] | |
| | Smallwood and Lapsley (1997) [29] | |
| | McInnes et al. (2000) [30] | |
| | Gandjour et al. (2001) [31] | |
| | Pagliari and Grimshaw (2002) [32] | |
| | Graham et al. (2003) [33] | |
| | Burgers et al. (2004) [34] | |
| | Brainin et al. (2004) [35] | |
| | Moreira (2005) [36] | |
| | Smolders and Braspenning (2005) [37] | |
| | Lui et al. (2006) [38] | |
| | Wright et al. (2006) [39] | |
| | Schunemann et al. (2007) [40] | |
| | <i>Articles on popular concepts in health care</i> | |
| | | Grol (2001) [41] |
| | | Swinkels et al. (2002) [42] |

Results

We categorised the studies into empirical studies that studied guideline development in practice, and non-empirical studies. Of the empirical studies, several authors specifically studied patient participation in guideline development. Van Wersch and Eccles [11] compared different participation methods in clinical practice by means of

a number of case studies. Van Wersch and Van Den Akker [18] and Jarret et al. [15] interviewed chairpersons and patient representatives, who had participated in guideline development groups, about their experiences. Lanza [9] reported on her experiences with patient participation in a focus group and survey research. Sieders [20], himself a patient representative in a development group, compiled his experiences in an extensive report consisting of, amongst others, e-mail messages and documents his patient organisation had developed as input for the process. The other empirical studies we found consisted of surveys amongst guideline developers that included a question on their ideas on, or their practice of patient participation [26, 33, 27]. Burgers et al. [34] analysed guidelines on oncology on quality criteria including patient participation. Smolders and Braspenning [37] did the same for guidelines on depression. In addition, several authors did a survey on patient communication preferences and compared these to the (draft) guidelines [4, 5, 10]. Goossensen et al. [17] also conducted a survey on patient preferences, but in this case the information was used in the guideline development process. Gandjour et al. [31] studied a guideline development process. In this guideline attention was paid to the stages in which patient preferences might be considered. Others performed case studies of guideline development (groups) in which patient representatives participated [28, 30, 32, 36, 38-40].

It is very difficult if not impossible to study the effects of patient participation using Randomized Controlled Trials (RCTs). One cannot very well imagine a research set up of guideline development groups with and without patient representatives, engaging in the exact same quest. Decision-making processes must be studied in different ways, for example by doing case studies, surveys, interviews and guideline analysis. Thus, the studies we found cannot be dismissed as methodologically flawed, many of them provide us with insights in complicated processes.

The non-empirical articles, first of all, consisted of literature reviews [6, 7, 14, 19, 22, 23, 41, 42]. Secondly, we found articles reflecting recommendations of committees or guideline developers on how to best develop and implement guidelines [12, 16, 24, 29, 35]. Two articles reflected on seminars that had been organised to discuss guideline development [3, 25]. Then there were articles that referred to some publications but that could best be categorised as statements of opinion [2, 8, 13, 21]. Finally, Nease and Owens [1] searched the literature and tested a model on the cost effectiveness of incorporating the preferences of individual patients into clinical practice guidelines. An overview of the nature of the studies is presented in Table 2.

Table 2 The nature of the studies

| Empirical studies | Non-empirical studies |
|---|---|
| <p><i>Studies of patient participation in guideline development</i></p> <p>Lanza (2000) [9] case study, patient participation through focus group and survey research (n=34)</p> <p>Van Wersch and Eccles (2001) [11] case studies of four participation methods</p> <p>Jarret et al. (2004) [15] evaluation study interviews patient/carer participants and chairs of guideline development groups</p> <p>Van Wersch and Van den Akker (2005) [18] process evaluation 2 guideline development processes, interviews with participants</p> <p>Sieders (2006) [20] experience report patient participant guideline development group</p> | <p><i>Literature reviews</i></p> <p>Owens (1998) [6]</p> <p>Bauchner and Simpson (1998) [7]</p> <p>Grol (2001) [41]</p> <p>Swinkels et al. (2002) [42]</p> <p>Cavelaars et al. (2002) [14]</p> <p>Crawford et al. (2002) [22]</p> <p>Schunemann et al. (2006) [19]</p> <p>Nilsen et al. (2006) [23]</p> |
| <p><i>Survey on patient preferences in relation to the guideline</i></p> <p>Butow et al. (1996) [4] survey (n=148) on communication preferences of cancer patients</p> <p>Schofield et al. (1997) [5] survey patients (n=84), doctors (n=64), nurses (n=140) perceived relevance and importance guideline</p> <p>Rankin et al. (2000) [10] survey (n=140) breast cancer patients on information preferences</p> <p>Goossensen et al. (2005) [17] survey on preferences anxiety disorder patients (n=140), interviews with patients (n=25)</p> | <p><i>Expert committees/ guideline developers</i></p> <p>Field and Lohr (1992) [24]</p> <p>Smallwood and Lapsley (1997) [29]</p> <p>Brainin et al. (2004) [35]</p> <p>Van Veenendaal et al. (2004) [16]</p> <p>Kelson (2001) [12]</p> |
| <p><i>Survey among guideline developers including a question on participation of patients in the development process</i></p> <p>Carter et al. (1995) [26] survey guideline development organisations (n=55)</p> <p>Grilli et al. (1996) [27] survey physicians (n=216)</p> <p>Graham et al. (2003) [33] survey guideline development organisations (n=730)</p> | <p><i>Seminars</i></p> <p>Gilmore (1993) [25]</p> <p>Duff et al. (1996) [3]</p> |
| <p><i>Analysis of guidelines on among other things patient participation</i></p> <p>Burgers et al. (2004) [34] analyses of 100 guidelines in 13 countries</p> <p>Smolders and Braspenning (2005) [37] analysis of the Dutch depression guideline</p> | <p><i>Opinion articles</i></p> <p>Bastian (1996) [2]</p> <p>Williamson (1998) [21]</p> <p>Saltman (1998) [8]</p> <p>Rogers (2002) [13]</p> |

Table 2 The nature of the studies (continued)

| Empirical studies | Non-empirical studies |
|---|---|
| <p><i>Studies of guideline development processes on among other things patient participation</i></p> <p>Eccles et al. (1996) [28] 2 case studies, patient representative participated in the group</p> <p>McInnes et al. (2000) [30] case study, consumer representatives participated in the group</p> <p>Gandjour et al. (2001) [31] case study, no participation but subjects were identified on which patient preferences should be considered</p> <p>Pagliari and Grimshaw (2002) [32] case study, patient advocate in the group</p> <p>Moreira (2005) [36] 2 case studies, patient representatives participated in the group</p> <p>Lui et al. (2006) [38] case study, consumers participated in the group</p> <p>Wright et al. (2006) [39] case study, draft guideline workshops including service users</p> <p>Schunemann et al. (2007) [40] case study, consumers were asked to provide feedback</p> | <p><i>Model</i></p> <p>Nease and Owens (1994) [1]</p> |

Patients and guidelines: the ideas

Our literature search showed that patient involvement in guidelines became a subject of interest from the early 1990s onwards. We identified two strands of thought in the literature:

1. Authors who argued that it is important for patients to participate actively in the guideline development process.
2. Authors who argued that guidelines should accommodate individual patient preferences without seeking active patient participation in the guideline development process.

We begin by discussing the focus on active participation of patients in guideline development. It is argued that participation is a consequence of the increasing importance of consumer choice in health care as we pointed out in the Introduction [2, 13]. The first strand of thought pleading strongly for active participation can be found in the articles by Bastian [2] and Duff et al. [3]. In 1996, Duff et al. [3] reported that patient participation in guideline development had indeed been put into practice from time to time, but not nearly enough. Both Bastian [2] and Duff et al. [3] argued that patients should be involved actively in the development process using different

strategies such as co-opting consumer representatives into the guideline development group, a literature search into patient preferences, and community consultation. At this time other studies show that there is little support for this amongst doctors and guideline developers, however [26, 27]. Still, it is argued by Bastian and Duff et al. that a truly collaborative approach should be taken and that this would enable patients to climb Arnstein's ladder of participation. Arnstein (1969) developed a ladder of citizen participation consisting of the rungs: manipulation, therapy (together non-participation), informing, consultation, placation (together tokenism) and partnership, delegated power, citizen control (together citizen power). Over the years, similar versions of a ladder of participation have been developed including one for patient participation in guideline development [16]. Other authors followed the line of reasoning of Bastian and Duff et al. using three sets of arguments for active patient participation: improved quality, increased legitimacy and principle-based desirability (ideology). Nineteen provided arguments in favour of active patient participation; all of them arguing that this would lead to better decision-making, hence improved quality [2, 3, 7, 8, 11-14, 16-18, 21-23, 27, 30, 34, 41, 42]. Because of their experience with health care services, patients supposedly have additional knowledge over and above that of physicians and researchers. Hence, their participation may lead to better health care. Integrating patient preferences into the guidelines will make them more applicable to health care practice and, therefore, the chance of implementing the guidelines is increased.

The second set of arguments claims that patient participation increases the legitimacy of the guidelines, since all parties were involved and the process was more open [2, 14, 16, 18, 22, 23, 27]. The third line of argument is principle-based [2, 14, 22, 17, 23, 13, 16, 18]. Authors put forward that patient participation is important simply because it is the right thing to do. Patients are the ones affected most by these decision-making processes and, therefore, it seems only fair that they should have a say in the matter. Furthermore, patients' participation could contribute to their empowerment as well as induce social change and shift the balance of power between the actors in the health care sector. Also, participation is politically desirable because it encourages participative democracy.

In contrast to the first strand of thought we found in the literature, the second strand of thought emphasised the importance of devoting space to individual patient preferences in the guidelines without seeking active patient participation in the guideline development process. Owens [6] argued that since patients' views about the quality of life with specific states of health and consequently about their preferred therapy can vary greatly, guidelines should not be written as if patients were all the same. To increase the quality of the guidelines (their legitimacy, acceptability and usefulness), guidelines should include recommendations on topics on

which patients' preferences vary, specifying how doctors can help patients choose according to their preferences. Other authors supported this plea for devoting space in the guidelines to accommodate individual patient preferences [1, 25, 31]. Thus, guidelines can help make the individual patient-doctor contact more patient-centred, a paradigm that is, as we stated in the Introduction, very strong in modern health care (Bensing 2000, Salmon and Hall 2003, 2004).

The first strand of thought -active patient participation in the guideline development process- has become dominant in the discussion on patient-centred medicine with regard to guidelines (Table 3). Although a number of authors stressed the importance of both active patient participation in the development process and individual patient preferences, the latter argument has become rare in recent years. Even though authors differ on how intensively and in what way it should be achieved, most agree that patients should participate actively in the process. Since active participation in the guideline development process has become the dominant argument we concentrate on it in the following section.

Patient participation in guideline development: practice

Increasingly, patient participation is being put into practice. After a survey amongst developers of 730 Canadian guidelines that were published between 1994 and 1999, Graham et al. [33] concluded that in 19.6% of them patients and consumers were involved in the development committees. This number has increased steadily in these years; 51% of the guidelines drawn up in 1998-1999 were developed with patients participating in the committees.

The message conveyed by these articles and documents is that involving patients in guideline development is a good thing. We did not find any articles that opposed patient involvement, although apparently doctors and guideline development organisations did not always look forward to the idea [26, 27]. The articles that did not specifically address the practice of participation did all advocate it, even though Nilsen et al. [23] concluded on the basis of a systematic review on patient participation in decision-making that there is a lack of research that reliably investigates whether consumer involvement actually delivers what it is supposed to (improved quality and legitimacy). Because of this lack of clear evidence authors simply stated that they believe patient participation is important. Alternatively, they referred to literature that showed that patients and health care professionals hold different opinions on certain subjects and thus concluded that both parties ought to have a say in guideline development. For instance, Bauchner and Simpson [7] referred to a study that showed that parents and health care professionals think differently on diagnostic testing and diagnostic error.

The lack of evidence for the claims made can be explained by the fact that patient

Table 3 Patients and guidelines

| Room for individual preferences in guideline | Active patient participation in guideline development | Room for both individual preferences and active participation in guideline development |
|--|---|---|
| <p>Gilmore (1993) [25] Nease and Owens (1994) [1] Owens (1998) [6] Gandjour et al. (2001) [31]</p> | <p>Carter et al. (1995)* [26] Bastian (1996) [2] Duff et al. (1996) [3] Grilli et al. (1996) [27] Eccles et al. (1996) [28] Bauchner and Simpson (1998) [7] Lanza (2000) [9] Rankin et al. (2000) [10] Grol (2001) [41] Van Wersch and Eccles (2001) [11] Kelson (2001) [12] Swinkels et al. (2002) [42] Cavelaars et al. (2002) [14] Pagliari and Grimshaw (2002)* [32] Crawford et al. (2002) [22] Graham et al. (2003) [33] Moreira (2005)* [36] Burgers et al. (2004) [34] Jarret et al. (2004) [15] Brainin et al. (2004) [35] Van Veenendaal et al. (2004) [16] Van Wersch and Van den Akker (2005) [18] Smolders and Braspenning (2005) [37] Lui et al. (2006) [38] Schunemann et al. (2006) [19] Sieders (2006) [20] Wright et al. (2006)* [39] Nilsen et al. (2006) [23] Schunemann et al. (2007) [40]</p> | <p>Field and Lohr (1992) [24] Butow et al. (1996) [4] Smallwood and Lapsley (1997) [29] Schofield et al. (1997) [5] Saltman (1998) [8] Williamson (1998) [21] McInnes et al. (2000) [30] Rogers (2002) [13] Goossensen et al. (2005) [17]</p> |

*These studies report on active patient participation but do not express views on its desirability.

participation in guideline development was not the main focus of all these studies. However, when reading the literature it also seems that the importance of patient involvement in guideline development was considered self-evident. For instance, Saltman [8] argued that clearly it is appropriate for consumers to be involved. That it is considered self-evident is also demonstrated by the fact that several authors stated as a matter of fact that patients had been involved in the guideline development processes researched by them [32, 36, 38-40]. Graham et al. [33] considered it a bad thing if patients had not been involved. This attitude can be interpreted as a sign that patient participation has become standard practice.

We now take a closer look at the studies that do report on experiences with patient participation in practice. We concentrate on the participation methods that were used, the effects of participation and the difficulties encountered in the process.

The literature mentions several methods of patient participation. One such method is to carry out a survey into patient preferences on a certain subject at the time of guideline development [9, 10, 17]. Apparently, such surveys are often not feasible because of budgetary constraints [14]. Surveying patient preferences can, of course, also be part of the literature search of the guideline development group in the sense that the state of the art concerning patient preferences is distilled from the literature rather than organising a fact finding mission oneself. Such a literature search is generally not considered a form of active patient participation in guideline development. Other methods of active participation mentioned in the literature are patient focus groups, in which insight can be gained on patient preferences which can be used as input in the guideline development process. Patient participation can also be put into practice by letting patient representatives give feedback on draft guidelines. Another method is enrolling patient representatives in the guideline development groups. The latter method is mentioned most in the literature.

Van Wersch and Eccles [11] are the only authors who compared different methods of participation in practice. They studied the following methods:

- (i) co-opting a patient into the guideline development group,
- (ii) organising a one-time focus group,
- (iii) holding a workshop where patients came together four times, and
- (iv) co-opting a professional patient advocate into the development group.

The authors studied these four methods through a series of case studies within the North of England evidence-based guideline development program. The authors came to the conclusion that overall the individual patients in the guideline development groups have very little input. Patients contribute most on the subject of

patient education, although subsequently their contributions are not acted upon. In the one-time focus group patients are most interested in patient education and self-management. They also suggest ways of making guidelines better accessible to laypersons. The patients in the focus group have difficulties with the medical terminology and the authors questioned whether they understand scientific evidence on cost-efficiency. The workshop method is resource intensive. In order for them to understand the process patients are taught through role play how the guideline development procedure works. They also put forward some suggestions to make the guidelines better accessible to laypersons (changing colours, the use of strong/weak evidence instead of A, B, C, D, using brand names, etc.). The patient advocate in the group understands the terminology and can contribute to the process. However, she is not herself a patient. The authors concluded that consumers should be involved in all stages of guideline development by using several methods at once, and supporting patients throughout the process. Other studies arrived at similar conclusions. Authors usually observed a paucity of information on which methods work best and that it is, therefore, desirable to use different methods at once [2, 3, 11-16]. None of the studies concluded that this lack of evidence is a reason to stop patient participation.

Patients' experiences with participation vary. A study on the experiences of patient representatives in development groups and chairpersons of these groups in the British National Health Service (NHS) guideline development process, showed that most of them look back on a positive experience [15]. Accounts of patient representatives who do not evaluate their efforts as positive were also found [18, 20]. Sieders, a volunteer patient representative himself, advises other patients, who might consider participation in a guideline development group, against doing so [20].

Participation in guideline development: not an easy task

Most authors argued in favour of patient participation in guideline development because, supposedly, it increases the quality of the guidelines. There is, however, little evidence in support of this supposition. Van Wersch and Eccles [11, p. 15] even concluded that: 'having involved consumers within the guideline development process (...) did not necessarily alter the content of the guidelines'. Schunemann et al. (2007) [40] concluded that the feedback of consumers on the WHO H5N1 virus guideline did not differ importantly from the panel, which consisted of clinical, methodological, basic science experts and country representatives, and there were no additional outcomes identified. Patients' contribution to the process is mostly on issues of communication and patient education [11, 12, 15, 17, 18, 22, 30]. What subsequently happens to their input and what it consists of exactly is not clear. After a patient sur-

vey on the need for psychosocial care for breast cancer patients one study concludes that the findings suggest that the draft guidelines adequately reflect consumer opinions [10]. The article is not clear about patient participation in the development of the draft guideline, so it is not possible to determine whether the guideline's fitting contents were the result of patient input at an earlier stage. This difficulty of assessing the contribution patients make to the decision-making process is not only seen in guideline development but in other decision-making processes as well [23]. It is interesting to note that in the descriptions of the participation process in guideline development groups, studies concentrated on the question whether patients are up to the task instead of concentrating on their contribution to the content of the process. The general conclusion was that patients can participate provided they are given proper support. For instance they should be trained to perform the task and chairpersons of the development groups should make sure that patients can deliver their input. The studies therefore conclude that certain adjustments in the participation process are warranted for participation [11, 12, 14, 15, 18].

Nevertheless, several difficulties were identified that cut deeper. There is uncertainty amongst participants about the goals of participation [9, 11, 13, 18] and patients have difficulty following medical jargon and assessing technical medical literature [14, 15, 12, 13, 19, 11, 18]. Several authors pointed out that as a consequence the patients gave little input [11, 12, 18, 28, 36]. According to Eccles et al. [28, p. 48] patients in the development group were 'often non-participating observers of technical discussion to which they could offer no input'. The difficulties identified can lead to high selection standards for patient candidates. For instance, one of the qualifications on the job description for a prospective member in the guideline development group used by the National Institute for Health and Clinical Excellence (NICE), part of the NHS and responsible for the development of guidelines, is the ability to understand scientific articles [15]. If, however, only highly educated patient representatives are recruited, how representative is the patient input? Some studies acknowledged this problem [3, 17, 19]. For example, Goossensen et al. [17] argued that with a patient representative in the development group, the opinion of a small, articulate group is represented. Therefore, a survey of patient preferences is proposed in addition to this form of participation.

Another difficulty that is encountered is the integration of patients' experiential knowledge in an otherwise evidence-based guideline [11, 15, 18, 37]. Sometimes patients' input is not taken seriously because it is not based on scientific evidence. Van Wersch and Van Den Akker [18, p. 20] even concluded that patient representatives felt that 'experiential knowledge was not considered as knowledge at all'. This could well lead to disappointment amongst the patient representatives involved [18, 20, 37].

Such intensive participation processes involve considerable costs, an aspect that is almost completely ignored in the literature. The guideline development organisation has to invest a considerable amount of time and money. More importantly, the process also requires a substantial amount of time and effort from the patient representatives who participate in guideline development groups. A volunteer patient representative in the guideline development group on eating disorders in the Netherlands calculated that his efforts had cost him a total of 2,000 h. He had tried to adhere to the evidence-based medicine (EBM) structure of the development process and had searched medical databases for publications. In other words, he had become a full member of the group. Still, he felt that his contribution was not taken seriously. The patient organisation he represented, therefore, did not endorse the guideline [20].

These problems encountered in the practice of patient participation in guideline development do not seem to be easily overcome by training or support of patients.

The future

At the beginning of this debate it was argued that not much is known about the contribution of patients in practice or what methods should be used [3, 7]. Presently, 10 years later, these questions still remain unanswered [23]. After identifying the existing difficulties authors concluded that it is important to continue the participation process and that it should, therefore, be improved and intensified. Many authors argued that a combination of methods should be used, including active participation, throughout the development process. Most authors concluded that patient representatives should receive more guidance during the process. Patient participants ought to be trained, prepared and educated to fulfil their task [11, 12, 14, 15, 18]. Moreover, further research is recommended on how to make a success of the development process. Few if any authors argued for less intensive methods. Except for Sieders [20], who advised patients against participating in a development group, and Eccles et al. [28], who proposed, after having studied patients in action in guideline development groups, that this is not the correct way to include patient input. They argued for a focus group. Another study argued for a survey as a viable alternative [10]. However, Cavelaars et al. [14] concluded that doing a survey at the time of guideline development is very costly and not a plausible alternative for that reason.

We conclude that most authors do not recommend less intensive patient participation nor do they search for less active ways of incorporating patient preferences.

Discussion

Creating room to accommodate patient input in guidelines has been a subject of

discussion since the 1990s. We identified two strands of thought in the early years of the debate. The first was to let patients actively participate in the process of guideline development through the use of focus groups and surveys, but especially by co-opting patient representatives into the development group. The second was to include recommendations in the guidelines that specify the importance of attention to individual patient preferences at the physician-patient level. The first strand of thought has become the dominant one in the debate. The most important argument in its favour is that patient participation would improve the quality of the guidelines. Other arguments are principle-based or stressed the increased legitimacy of decision-making.

Is active participation patient-centred?

Although the general consensus seems to be that patients should be involved in guideline development, the added value of their participation has yet to be established. When participation is studied in practice the conclusion is usually that patients can participate provided they receive proper support. Apparently authors assume that patients can be trained to become full members in a guideline development group and therefore ought to be included. However, training and supporting patients to be able to participate as full members in an EBM guideline development process is a double edged sword; one can wonder whether this is the right way to go forward. Patients who have been trained and supported become fellow academics; they may no longer be able to contribute the experiential knowledge for which they were asked to participate in the first place. Patients who were not properly trained do contribute this experiential knowledge, but studies have shown that it is difficult to incorporate this in EBM guidelines.

When empirical evidence for something (a treatment, a management strategy, a decision-making process) is not found, two options may be considered. Firstly, it could be argued that more research should be done and conditions should be improved so as to make the proposed practice a success. Secondly, it could be argued that it is time to explore other alternatives. The existing literature on patient participation in guideline development proposes the first option. We feel it is important to broaden the debate and that it is time to consider the second. In our view, the results in the literature show that active participation in guideline development is not the best way towards making health care more patient-centred.

We do not argue that patient preferences are not important. On the contrary, patients who want to be involved in decisions about their health and health care should be given the opportunity to do so, and guidelines can help to make this possible. The other line of reasoning, room for individual patient preferences in the guidelines, which has largely disappeared from the debate, could be reconsidered

to accomplish this. This should not be considered as a step backwards in patient-centred medicine but rather as a way to best accomplishing it. Apart from the fact that the use of active participation has yet to be established, there is even the possibility that patient involvement in the guideline development process could hamper patient-centred care at the individual level. When the suggestion is raised that patient preferences have already been incorporated in the guidelines, the danger is that this could become a reason for the users of the guidelines not to pay as much attention to preferences at the individual level. A guideline based on active participation of all actors involved becomes a consensus document from which it could become difficult to deviate in individual cases.⁴ The methods used for participation, such as co-opting a patient representative into the group, are supposed to provide input regarding what 'the patient' with a particular disease or condition prefers and what 'the patient' experiences. Consequently, the uniqueness of every patient that is emphasised at physician-patient level is no longer reflected in the guidelines. Furthermore, since the contribution of patients to this process has yet to become clear the suggestion that patient preferences have already been incorporated in the guidelines is even further off the mark.

Attention in the guidelines for individual patient preferences can be accomplished by including a separate section or chapter on patient-physician communication the importance of which for patients was repeatedly stressed in the literature (Butow, Kazerni et al. 1996; Schofield, Walkom et al. 1997). Recommendations can be given on how professionals could best organise this process. As we saw earlier, these issues are also raised by patients when they do contribute to the development process, implying that they already recognise its importance. Since it is not clear what becomes of these suggestions when they are raised by a patient in a group, we recommend attention be paid to this subject in all guidelines. A special patient version of the guidelines might further help individual patients in their decision-making process and should, therefore, be made available to patients who want to be actively involved in their own care. Research into patient preferences on these issues can still be used as input for the guidelines. For instance, surveys, or other types of research, could be done to determine the views of patients with a certain condition. If it is concluded that there is a paucity of such studies, as is sometimes done in the literature, it should be placed on the health research agenda.

Research into patient preferences can be used as evidence in the development

⁴ Taking into account every possible argument in the development process other than medical evidence will make deviation from these guidelines ever more difficult. Other arguments that are already used are cost-efficiency, safety, usability, organisational feasibility and judicial considerations (Wiersma and Burgers 2004).

process, but it should still be made clear that this research merely serves as a general overview of patient preferences and that it does not represent an individual patient's preferences. Professionals involved in the development process and who have the necessary skills to perform such literature searches, can be trusted to take these studies into account in their literature search. There is no compelling reason why patient representatives should be trained to perform this task.

Other reasons for participation

The above argument is relevant whenever the stated goal of active participation is to improve the quality of the guidelines. As we have seen, however, there are other arguments in the debate in favour of active participation. Legitimacy, in the sense that decisions are made in all openness with patients functioning as a kind of referee so the participants keep their eyes on the ball, can be seen as an important goal. Other arguments can also still apply. For instance, the normative argument that patients should participate in health care decision-making since they are the ones directly affected by it. Participation then becomes more of a goal in itself. One could, of course, argue that democratic participation in guideline development is not a process that is primarily supposed to improve the quality of the guidelines. Democracy has many advantages. Nevertheless, ever since Plato, people interested in the quality of decisions have argued that improving the quality of decisions is not one of them. The democratic constitution of guidelines may be considered valuable for other reasons. For example, it may be good for people to participate in decision-making processes. De Tocqueville (2000, p.125) regarded the citizen jury as "one of the most effective means that the society can use for the education of the people". He saw jury duty not as something that would be beneficial for improving the quality of the judicial outcome, but as something that is good for educational purposes: "I do not know if the jury is useful to those who are parties to lawsuits, but I am certain that it is very useful to those who judge them." (ibid. p.125). In this connection Gastil and Weiser (2006) recently concluded that the jury promotes civic engagement; not only do they find that jury service spurs increased electoral participation, but it also broadens civic engagement such as an increased tendency to discuss public affairs and staying informed. These educational or empowerment purposes could also be an argument for asking patients to participate in decision-making processes. The group of people that is reached through the participation process would be quite small compared to the number of people involved in a citizen jury system. However, if patient participation in health care decision-making were viewed as part of a larger tendency to include citizens in decision-making processes, this would not be a problem. For some patients this empowerment could be especially important because their condition makes it difficult for them to work and participation in health

care decision-making can provide an important means towards feeling useful again. Crawford et al. (2002) concluded that patients' self-esteem improved as a result of their contributions. This could be considered a legitimate reason to continue participation processes. However, if civic education were the main reason to promote patient participation, certain participation methods should not be continued. At present, some patient representatives are paid staff members employed by a patient organisation, who have never experienced living with the condition themselves. The civic education goal would be lost on such participants.

Another principle-based argument in favour of patient participation might be the balance of power or checks and balances. Patients are dependent on health care professionals, they are affected by their decisions, and hence one might argue that their presence in each and every organisation or forum involved in health care decision-making should be considered necessary as well as self-evident. Even if their involvement does not change the content of the guidelines much, it could make all parties in health care at least feel more like partners. When the principle-based desirability is a position generally adhered to, it could be concluded that it is important to continue with active participation. However, then these arguments should also be the ones used in the discussion. This could prevent disappointment amongst participants who expect to have a great deal of influence on the content of the guidelines or who want to fully understand the whole process but cannot. Apart from this it would still be important to create room for individual patient preferences in the guidelines and not to present them as if thanks to the participation of patient representatives patient preferences have already been taken care off.

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CHAPTER THREE

GOVERNMENT INFLUENCE ON PATIENT ORGANISATIONS

This chapter was accepted for publication as:

Van de Bovenkamp H.M., M.J. Trappenburg, Government influence on patient organisations, *Health Care Analysis*

Introduction

In the last two decades many Western welfare states have granted their citizens more choice and more influence in the provision of public services (housing, education, home help, health care) be it for democratic reasons (people should have a say in whatever affects them), for reasons of efficiency (citizens should be able to point out what they really need, rather than be granted a standard provision), or to enhance the quality of service delivery (professionals learn from actively choosing and participating citizens what works and what doesn't) (Clarke, Newman et al. 2007). Health care is a public sector in which active participation by citizens is supposed to do a world of good. It is widely recognised that health care professionals should take leave of the traditional model of paternalist medicine in which the doctor knew what was best for his patients. They should now adhere to a model called 'shared decision making' in which patient and doctor discuss treatment options together and then decide what to do (Collins, Britten et al. 2007).

In many modern health care systems patients not only participate in decisions concerning their own health and medical treatment. Increasingly patients also participate in all sorts of decision-making processes at the meso and macro level (Baggott, Allsop et al. 2005; Van de Bovenkamp, Trappenburg et al. 2010; Baggott and Forster 2008). Patients participate in decision-making on many different subjects, such as government policy, medical guideline development, research agenda setting, insurer policy and provider policy (Van de Bovenkamp, Trappenburg et al. 2010; Crawford, Rutter et al. 2002; Caron-Flinterman 2005; Ross 1999, Syrett 2003).

The most often cited reason for patient participation is that patients bring an additional perspective based on their experiential knowledge to the table, which may improve the quality of decisions. Patient participation could thereby also increase the overall effectiveness and efficiency of the health care system, since patients might offer solutions which fit the preferences of patients better, thereby hopefully preventing mistakes and saving costs. For example when patients are well-informed compliance will improve and patients may learn how to manage their own care (Grit, Van de Bovenkamp et al. 2008; Epstein 2008; Hanley, Truesdale et al. 2001; Boote, Telford et al. 2002; Hewlett, De Wit et al. 2006). Patient participation is also proposed for democratic reasons. Democratic legitimacy would increase when patients participate; parties who reap the benefits or suffer the consequences from certain decisions ought to have a say in the process. Participation might also have an empowerment effect on those who participate; patients who are given a say in policy processes acquire a sense of self-efficacy (Van de Bovenkamp, Trappenburg et al. 2010; Caron Flinterman 2005; Baker 2007; Grit, Van de Bovenkamp et al. 2008). In short, the expectations of patient participation in health care decision-making are high. Research shows, however, that not all expectations are met (Caron-Flinterman

2005; Syrett 2003; Barnard, Carter et al. 2005; Van de Bovenkamp and Trappenburg 2009; Van de Bovenkamp, Trappenburg et al. 2010). Patients have difficulty in actually influencing the process. Sometimes patient participation is mere tokenism (Syrett, 2003) and at other times patients are put to instrumental use by more powerful actors in health care, such as care providers, insurers and guideline development organisations (Harrison and Mort 1998; Van de Bovenkamp, Trappenburg et al. 2010).

According to researchers as well as policy-makers, the position of patients can be strengthened when they are organised. Civil society organisations such as patient organisations could play an important role in facilitating democracy and bringing the interests of certain groups to the fore (Baggott, Allsop et al. 2005; Coxall 2001; Putnam 2000). However, the difficulties encountered with regard to individual participation seem to pop up also when participation takes place through patient organisations: representatives of patient organisations may also be manipulated, and representatives of patients do not always feel able to really influence decision-making processes (Baggott, Allsop et al. 2005; Van de Bovenkamp, Trappenburg et al. 2010; Baggott and Forster 2008). It is therefore argued by policy-makers, patient organisations and researchers that patient organisations should professionalise in order to strengthen their position (Baggott, Allsop et al. 2005; Trappenburg 2008; Nederland and Duyvendak 2004). To professionalise patient organisations need money. Often membership dues are insufficient to finance paid staff members. If membership dues are too high, patients will choose to do without membership, as much of the information which used to be provided by patient organisations is now freely available on the internet (Newcome Research & Consultancy B.V. 2006). Hence patient organisations have to search for additional funds. One way of increasing their financial means is through donations by the pharmaceutical industry. However, this strategy is heavily contested, since accepting money from the pharmaceutical industry may threaten the organisations' independence and may increase the danger of being put to instrumental use (Baggott and Forster 2008; Jones 2008; Lofgren 2004). As the input of patients and the role of patient organisations are valued by many it is therefore argued that government should subsidise these organisations to enable them to play a strong role in health care decision-making. In several countries government subsidises patient organisations (Baggott, Allsop et al. 2005; Nederland, Duyvendak et al. 2003; Leys, Reyntens et al. 2007). In this chapter we will explore the ties between government and patient organisations in the Netherlands to see whether this is a viable strategy to ensure patient participation in decision-making while keeping patient organisations out of the hands of the pharmaceutical industry.

Patient participation through patient organisations has perhaps gone furthest in the Netherlands (Van de Bovenkamp, Trappenburg et al. 2010). Dutch patient

organisations are called the official 'third party' in health care, next to health care insurers and providers. This role has been assigned to them by the Dutch government and means that they are asked to participate in many official decision-making processes to represent the patient perspective (ibid.). Patient organisations have become 'insider groups', which means that they are regarded as legitimate players by government and are consulted on a regular basis (cf. Grant 1989). At present there is a wide variety of patient organisations in the Netherlands (Nederland, Duyvendak et al. 2003; Oudenampsen, Kamphuis et al. 2008a). There are over 300 different organisations, about 200 of which are disease specific organisations (Berk, Van der Steeg et al. 2008).⁵ Together the disease specific organisations have about half a million members (Oudenampsen, Kamphuis et al. 2008a). Besides these organisations, there are disease group umbrella organisations⁶ and regional and national umbrella organisations. The members of these umbrella organisations are not individual patients but other patient organisations. All patient organisations together are often referred to as 'the patient movement' (Nederland, Duyvendak et al. 2003; Oudenampsen, Kamphuis et al. 2008a).

Dutch patient organisations rely on several financial sources. On average 27% of the funding of disease specific organisations comes from member contributions (Oudenampsen, Kamphuis et al. 2008a). Some patient organisations receive funding from the pharmaceutical industry. On average 8% of the budget of patient organisations that are sponsored by the industry comes from the industry (Rijn van Alkemade 2005). Obviously, not all patient organisations are sponsored. Some organisations are simply not interesting for pharmaceutical companies because they represent patients who suffer from a disease or affliction that cannot be cured by medication. Other patient organisations (like the client organisation for mental health patients) do not want to be sponsored by the pharmaceutical industry on principle.

There has been quite a lot of debate, also in the media, about the ties between patient organisations and the pharmaceutical industry, which are generally disapproved of (Trappenburg 2008, Bouma 2006). In response to this situation some members of Parliament argued that these financial ties are undesirable and that government funding should increase to prevent undesirable connections (TK30482 no.2). In the Netherlands government subsidies were already granted to patient organisations in the 1980s. Today government subsidies constitute 46% of the income of disease specific organisations (Oudenampsen, Kamphuis et al. 2008a). Umbrella

⁵ Examples of disease specific organisations are the Parkinson Association, the Epilepsy Association and the Lung Cancer Foundation.

⁶ For example the Lung Cancer Foundation and other cancer organisations are part of the Dutch Cancer Federation (NFK).

organisations also rely heavily on government subsidies. The budget of national umbrella organisations like the National Patient and Consumer Federation (NPCF) mostly consists of government subsidies⁷ (NPCF 2008).

Although government funding can enable patient organisations to become stronger players in the health care field while keeping them out of the claws of the pharmaceutical industry, it does not guarantee their independence. Government subsidies also come with strings attached and put patient organisations under at least some government control (Baggott and Forster 2008). In this chapter we will explore what happens when patient organisations have government as their facilitator. We will answer the following research question: *In what ways does the Dutch government influence patient organisations and how should the ties between government and patient organisations be assessed?*

Answering this question is important for several reasons. First of all it is important to analyse what happens when patient organisations are facilitated and subsidised by government, because this is also proposed in other countries (Baggott, Allsop et al. 2005; Jones 2008; Leys, Reyntens et al. 2007). Our study of the Dutch case may help to reflect on the desirability of such a policy. Secondly, answering this question may be important for scholars who are interested in neo-corporatism and policy networks. To our knowledge a large part of the research on neo-corporatism and policy networks focuses on the way interest groups influence policy-making and discusses whether this influence is desirable (see for instance Akkermans and Nobelen 1983; Cawson 1986; Klein 1994; Williamson 1989). We feel it might be worthwhile to consider the opposite question. How does government in such a relationship influence interest groups (in this case patient organisations) and is this influence desirable? Although policy network theorists argue that interaction between government and groups in the policy network causes two way influence relations (Bagott, Allsop et al. 2005) and although researchers sometimes observe that giving groups an insider status poses the danger of becoming 'servants of the centre' (Isaac-Henry in Grant 1989), the influence relationship from government to civil society organisations does not receive much attention in the literature. We feel it is important to learn more about the way government influences civil society groups.

In this chapter we will first describe the methods used in our study. Following that we will describe Dutch government policy directed at patient organisations and the response of these organisations to this policy. In the Conclusion and Discussion section we will argue that governmental influence on patient organisations is strong in the Netherlands, that the ties between government and patient organisations

⁷ In addition the NPCF receives funds from their members (other patient organisations) and some of its income comes from organised activities (NPCF 2008).

have both positive and negative consequences and that the latter may be a reason for all parties involved to critically assess this situation.

Methods

To study the ties between Dutch government and Dutch patient organisations we used different research methods. First we analysed official policy documents regarding patient organisations to gain insight into the ideas of government about these organisations. Our policy document search showed that patient organisations have been a subject of government interest from the early 1980s onwards. Our analysis therefore consists of documents from 1980 till June 2009. An overview of the policy documents used can be found in Table 1. An analytical scheme was composed after reading the documents. We scrutinised all documents on the government's ideas about: (1) the organisational structure of the patient movement, (2) the activities patient organisations should perform, (3) the ideology of patient organisations and (4) the funding and accountability of patient organisations. This enabled us to analyse different aspects of government policy toward patient organisations.

Quite a lot of empirical research has been done into patient participation and the role of patient organisations in the Netherlands. We studied this research to gain insight in (1) the activities of patient organisations, (2) patient organisations' experiences with all of these activities and (3) the way these organisations responded to government policy plans with regard to the patient movement. An overview of the studies used is presented in Table 2.

The analysis of the policy documents and the literature on patient organisations in the Netherlands provided us with a comprehensive picture of the relationship between government and the patient movement in the Netherlands.

Results

Most Dutch patient organisations were founded in the 1980s. They were founded by patients, but often in association with or supported by health care professionals (P8). Contacts between fellow sufferers, sharing information and providing peer support were generally the most important reasons for the foundation of these organisations (P8). People wanted information that they could understand about their own or their children's disease or condition and they wanted to share their stories and learn from other people's experiences (P8). Patient organisations provided these services which many patients and/or family members felt were important to deal with their situation and which were not provided by the professional health care system. For most patient organisations interest representation was not an important part of their activities during these early years. This was different for a few radical organisations in the mental health care sector which struggled to make mental health

care less medical and more democratic (P1, P8).

Once founded, patient organisations soon became a subject of government interest. Government policy was directed at influencing patient organisations in several ways. In the following subsections we will describe the government's policy to change their organisational structure, their activities, and their ideology and the response of patient organisations to each of the policy proposals. Lastly we will describe how government tried to hold patient organisations accountable through government funding and how this worked out for patient organisations. Interestingly the policy of the Dutch government directed at patient organisations seems to have followed a consistent path throughout the years, despite the fact that different political parties participated in government. Dutch political parties in subsequent governments seem to have had similar ideas about patient organisations.

Organisational structure

In 1981 an important white paper, entitled *Patient Policy* (G1), was published in which it was argued that users of care should have a say in the provision of care in health care institutions, regional advisory boards and in decision-making at the national level. Patient organisations were expected to play an important role in all of these decision-making arenas. However, according to this document, patient organisations were not organised in the right way to accomplish this. There were a lot of disease specific organisations that catered for members who were often too sick to participate in any kind of council. Even when their health was no obstacle to participation, they did not seem to be interested in participation, since only a small number of disease specific organisations had designated influencing policy as one of their goals. In addition it was identified that the different organisations did only sporadically work together. There were no regional organisations with a general interest in health care policy. A lack of money was considered to be an important cause of this lack of unification. Regional authorities were therefore asked to finance patient organisations in order to create and maintain regional patient platforms, which could represent the interests of patients and deliver expertise and knowledge in policy-making. In the first half of the 1980s regional platforms, financed with regional governments' money, were indeed created (G3). After their creation government tried to influence these regional platforms further, for instance they were admonished to give disease specific organisations a say in their activities so as to ensure that justice was done to the diversity of the movement (G15).

In the white paper *Patient Policy* (G1) government not only recommended patient organisations to organise themselves at the regional level; a national platform for patients and health consumers was proposed as well. The development of such a platform would be supported by government, and financing it was considered part

of this support. The national patient/consumer platform should be a suitable voice for patients' interests according to the government. To help position such a platform in the field it was further proposed that representatives of the platform should serve on a number of important advisory councils, such as the National Council for Public Health. In 1983 a national platform for patients and consumers, the LPCP (*Landelijk Patienten en Consumenten Platform*), was founded which employed activities on general patient interest representation (P8).

In 1988 a follow up white paper on Patient Policy was published (G3). In this paper it was argued that government policy should be directed at strengthening the position of patient organisations further by making sure that they increasingly worked together. To strengthen patient organisations' position subsidies would be increased. In another white paper on patient and consumer policy, published in 1992, the government announced that the kind of extensive participation in decision-making bodies expected from patient organisations required a patient movement organised more clearly and more consistently. Ideally there should be one identifiable powerful organisation which could count on broad support (G5). Government wanted an umbrella organisation that would represent a larger part of the patient movement than the LPCP did. This wish was granted almost immediately. In 1992 the National Patient and Consumer Federation (NPCF), a broader federation of coalitions of patient organisations, replaced the LPCP (G6). The national federation and some other organisations that provided patient organisations with support would be financed by the government, after having been evaluated on efficacy and cooperation possibilities (G5).

Government's interference with the organisational structure did not end with the push for umbrella organisations; the patient movement was also asked to make sure that there was no overlap between organisations. An evaluation of the working method of the NPCF was announced as a way to support the development of new strategies in the middle of the 1990s (G6). By the end of the 1990s the government announced that a trajectory would be started, the goal of which would be obligatory collaboration or integration of existing patient platforms (G11). In a letter to parliament the minister of health care announced that she had asked a consultancy firm to investigate how the NPCF and two other national platform organisations, the Council for the disabled and the Union for the organisations of the chronically ill, cooperated to see if there was any overlap or perhaps white spots in their activities (G13). Before the investigation was really carried out the Council for the disabled and the Union for the organisations of the chronically ill put two and two together and decided to merge (P8), which was applauded by the government (G15).

In 2001 the white paper *Choosing with Care* was published. Again the future of patient organisations was discussed and again government expressed its desire

that they should present a united front and that the department of health would keep a check on the way the different levels of the patient movement worked together (G15). This push toward more cooperation remained on the policy agenda throughout the years (G17, G18). In 2009 the government announced that it would like the different umbrella organisations to form one organisation. The umbrella organisations have agreed to think about this which pleases the minister of health care (G20). Cooperation increasingly dominates the agenda of patient organisations. Although many disease specific organisations still emphasise their uniqueness they start to acknowledge the need to work together, because of the ever increasing government induced demand for interest representation activities. Working together can strengthen their position, they feel. Moreover, it gives them the opportunity to professionalise. One patient organisation alone cannot afford to hire paid staff, but several organisations combined can, especially if working together is rewarded financially (P10). For example, several patient organisations concentrating on heart conditions have decided to merge in order to strengthen their interest representation activities (P13). Other patient organisations also increasingly work together in their interest representation tasks and in sharing information (P12).

In sum, we can say that the government successfully tried to change the organisational structure of the patient movement several times and continues its attempts to influence this structure.

Activities

Government policy also included recommendations for patient organisations to steer their activities. These directions became increasingly more specific. At first, the original activities of patient organisations, providing information and peer support, were valued greatly by the Dutch government (see for instance G6). In addition however, government would like them to perform more interest representation activities. In the beginning of the 1980s the lack of interest of many patient organisations in policy issues was identified with regret (G1). According to the government patient organisations should become much more active in formal decision-making processes.

In the late 1980s, government observed that many patient organisations had indeed become active in committees and councils. However, according to the government this still did not happen enough (G3). To facilitate their role in decision-making government awarded patient representatives seats in official advisory councils and pushed for their participation in decision-making on all kinds of levels (G3). Government also emphasised the importance of patient involvement in contacts with providers and insurers (G5, G6). According to the government, patient organisations should focus on influencing insurer and provider policy as the 'third party' in health

care, beside providers and insurers. However, since government still played an important role in health care policy-making it was argued that patient organisations should critically follow government policy as well (G6). The 'third party' discourse continues to dominate policy documents in the following years. Consecutive ministers of health care announced that patient organisations should be an equal partner to health care providers, insurers and the government (G14, G19). Patient organisations on their part report that although providing information and peer support is still important, interest representation, such as trying to improve the quality of care, stimulating scientific research and purchasing health care, has become very important as well and that this task has grown into a significant part of their activities. All other actors in health care, insurers, providers, government, researchers, intermediary and supervisory organisations, consult with patient organisations in one form or the other (P8, P9, P10, P11, P12, P14).

Government also increasingly specified which subjects patient organisations should become interested in. In the late 1980s for example government saw a role for patient organisations in decision-making on medical research. Government felt that its own role in scientific research should be more distant than before. Instead societal organisations ought to be involved in scientific research, including patient/consumer groups. According to the government this would lead to large societal support and enhance the implementation of the results of scientific research (G4). A spokesperson of the patient movement was awarded a seat on the Council of Health research, which has an important task in advising government on research priorities. Some years after this, patient representatives were asked as official reviewers to comment on research proposals at ZonMw, the organisation responsible for dividing the governmental research budget in the health care sector (P3, P11). Other initiatives include consultation of patient representatives by researchers (researchers are required to seek patients' advice if they want to be eligible for ZonMw research funds) and participation of patients in research committees (P6, P8). Some patient organisations also perform research on their own. Thus, patient organisations have taken these new tasks on board and try to influence research in different ways (P8, P11, P12).

Guideline development was another area of decision-making government felt to be important for patient organisations. In 1995 the minister stated that she would support the involvement of patient representatives in medical guideline development because of the experiential knowledge they would bring to the tables where professional guidelines were discussed. Patient organisations should want to and dare to carry joint responsibility for the content and the application of guidelines (G7) used by medical professionals to provide care according to the best medical knowledge. Many patient organisations do indeed participate in guideline develop-

ment since the end of the 20th century. They are asked to partake in guideline development groups with professionals, researchers and other experts in the field, by organisations that develop such guidelines and they try to do so as much as possible (P4, P10, P11).

In 2006 a new health care insurance system was introduced in the Netherlands, based on managed competition (see also Vaillancourt Rosenau and Lako 2008). This new system provided patient organisations with new participation possibilities. Patient organisations, as the official third party in health care, are expected to become a countervailing power to health care professionals and health care insurers on the health care market (G14). Patient organisations should make sure that patient preferences are central in the provision of care (G10, G18). In response to this governmental desire, patient organisations now consult with both health care insurers and providers to improve the quality of care that is provided. For example, although not standard practice yet, insurers consult with patient organisations to learn more about criteria for health care purchasing. Patient organisations also participate in quality projects of providers and insurers to identify points for improvement in hospital care. In addition some patient organisations try to monitor the quality of care that is provided, award quality marks to care institutions that provide care according to their criteria, and take action when they find instances of insufficient health care provision (P10). The new health insurance act also allowed and expected patient organisations to organise their membership into insurance purchasing groups to negotiate better benefits for their members. Some patient organisations immediately put this into practice. In 2007 around 50 collective contracts were closed by patient organisations (P7) and more patient organisations are trying to negotiate similar contracts. However, so far the contents of the collective contracts were not impressive. Patient organisations have not been able to negotiate contracts which offer better care for their members (P10, P14).

More activities of patient organisations were not only expected on the national level but on the local level as well. With the introduction of the Social Support Act (*Wet maatschappelijke ondersteuning, Wmo*) in 2007 patient organisations are expected to represent the interest of patients in municipalities. This act decentralises certain activities concerning the provision of care. Municipalities are obligated to involve a number of stakeholders, amongst others patient organisations. Since this is a recent development it remains to be seen how this policy works out in practice. It is clear, however, that at least a number of patient organisations do try to fulfil their expected role on the local level (P8, P9). A little over a quarter of them now have contacts with local government (P9).

In short, more and more tasks were assigned to and expected of patient organisations, which most organisations try to take on board. Patient organisations report

that they participate in as many decision-making processes as possible, which has led to a problem of overload. They are asked to participate in so many decision-making procedures that they cannot cope with the demand. This applies especially to smaller organisations, but larger organisations also experience this problem. Nonetheless many patient organisations express a wish for even more participation possibilities and increased government funding to enable them to play the role that is expected from them (P8, P14, G18). However, the fact that all their efforts do not lead to the powerful position they hoped for does lead to some frustration amongst patient organisations (P5, P8, P14). Although they have been given many opportunities to participate, patient organisations still experience a lot of difficulty in actually influencing decisions.

The case of patient organisations in the Netherlands shows that access does not necessarily equal influence (P14). For sure, there are shining examples of patient organisations that managed to change health care for the better. The HIV association and the Breast Cancer Association managed to change policy concerning medication distribution, through lobbying and media utilisation. The Association for Muscular Diseases is generally acknowledged as a driving force behind medical research in this area, since they are able to bring together experts and patients for diseases that only strike a small number of people. But in general patient organisations find it hard to influence decision-making processes. Most of the interest representation activities consist of taking part in formal decision-making procedures. This participation model can be described as neo-corporatist. Patient organisations attribute their lack of influence to the fact that they remain in a dependent position in this model; other actors in the field do not really need them to make decisions. So whenever there is disagreement, the more powerful actors in health care, such as insurers and providers, can easily disregard patient organisation representatives and continue anyway. Patient organisations can do little to prevent this (P14). This effect is reported on participation in decision-making processes with different actors. For instance, in the negotiations with insurers (patient organisations operating as insurance purchasing groups), in decision-making processes on research and in guideline development project teams (P5, P8, P10, P14). Patient organisations sometimes feel that other actors can show off with a seal of approval (approved by patient organisation X!) while not allowing them a real say in the process (P10, P14).

Ideology

Dutch government did not only steer the kind of activities patient organisations should perform, it also tried to determine in advance what their input should be in carrying out these participation activities; it tried to influence patient organisations' ideology.

From the very beginning government wanted patient organisations to be critical towards the medical profession. Organisations of health care professionals historically have a strong position in health care and patient organisations should be supported to counter this position (G1, G3). However, most patient organisations were founded in association with and supported by professional health care workers, which led to a less than critical attitude among disease specific organisations according to government (G1). Since health care workers and patients had 'structural intrinsically conflicting interests' this situation was deemed undesirable (G1). In the early days of the patient movement a more critical attitude toward the medical profession was displayed by general patient organisations (such as the non disease specific Association for Child and Hospital), by client organisations in mental health care and by general consumer organisations (which were active in representing the interests of consumers on all kinds of markets besides health care) (G1). The national platform that was founded in 1983 consisted of these critical organisations (P8), which meant that the national platform of patients had the desired critical attitude towards the health care profession.

In several policy documents the government emphasised that patient organisations should be 'professionalised' and that they should improve their expertise (G2, G5, G12, G15, G17, G18). This professionalisation also potentially affects the input of patient organisations since it implies a shift in focus of these organisations, since different knowledge and expertise is considered to be important. What the government meant by professionalisation was not always explained clearly, but it seemed to entail at the least that organisations should have a proper administration, that they ought to formulate policy goals, evaluate whether these goals were accomplished and that they ought to be able to participate in the decision-making bodies that the government wanted to open up for them. This meant that they should have highly qualified volunteers, or hire educated personnel. Apparently the experiential knowledge of the average patient active in a patient organisation could not deliver the input that government wanted from patient organisations. In consultation with the NPCF government announced a coordinated education program to improve patient organisations' expertise (G5). In 2002 the government concluded that the process of professionalisation had taken place according to plan (G16). An example of this professionalisation can be seen on the board of the umbrella organisation NPCF. The board no longer consists of (former) patients with experiential knowledge; several of its present members are business managers and economists (www.npcf.nl). What the effect of this composition is has not been properly researched yet. However, it is likely that the strong support for a market based health care system of the NPCF (the National Patient and Consumer Federation was among the more ardent supporters of the plan) had something to do with the composition of the board.

Many disease specific organisations are trying very hard to professionalise as well. It is agreed that participants need to be able to look beyond their individual experiences, have strong negotiating skills and organisational, financial, medical and scientific knowledge to be able to talk to the other actors at the negotiating table (P14). These organisations are therefore educating their volunteers, they try to recruit highly educated volunteers and increasingly hire professional employees, who are not expert patients themselves but have knowledge about interest representation (P2, P8, P10, P14). A little over half of the disease specific patient organisations still only work with volunteers. All other disease specific organisations and the umbrella organisations have professionals working for them to support their work (P9). Recently the minister of health care concluded that this professionalisation is not yet finished and more money is promised, so the patient movement can become a more powerful, equal party in health care (G18).

Funding and accountability

The Dutch government has put a lot of effort in steering patient organisations. Funding these organisations has been the most important instrument to do so. Patient organisations have increasingly been subsidised by the government from the 1980s onwards (G1, G3, G5, G8, G15, G16, G18). In 1996 the government created a special fund to distribute subsidies amongst patient organisations (G9, G16). In the beginning of the 21st century the amount of money to be distributed was raised several times because of the new health insurance system in which a more important role was expected of patient organisations (G10, G18).

Subsidising patient organisations gave government the means to enforce compliance and accountability. Granting subsidies entailed detailed supervision on how the money was spent. Over the years the requirements connected to the subsidies became increasingly far reaching. First of all patient organisations were required to be transparent and representative (G15). Government wanted them to especially focus on involving ethnic minorities for instance. In the policy paper *Choosing with Care* it was explicitly stated that if patient organisations would not comply with the governments demands the minister would reconsider the subsidy structure of the movement (G15). The financing structure has been changed several times over the years to increase governmental influence. Since 2001 the government has contemplated financing patient organisations “on the basis of performance” (G15). This financing structure was put into practice in 2006 and developed further in 2007 (G18). Financing on the basis of performance meant that patient organisations had to prove that they really performed the activities that were expected from them. This accountability regime enlarged government control.

In the 2009 government plans, subsidies for patient organisations consist of dif-

ferent parts. The first part is a basic subsidy, a second part is granted for “development purposes”. The criteria for this latter part of the subsidy are not clear yet; they will be established in consultation with “the field”, i.e. with representatives of patient organisations (G21). Thirdly patient organisations can apply for project subsidies. If they want to apply for a project subsidy they must draw up a four year plan in which they explain how their activities fit within certain subjects delineated by the government (G19).

Almost all patient organisations apply for government funding (P8). Moreover, patient organisations want government subsidies to increase because they feel they need more money to be able to perform the tasks that are expected from them (P8, P10). Since they are expected to play this role by the government, they tend to think that the government should enable them to do so by giving them the necessary financial means. And as they need these finances to perform all their activities they accept that they have to respond to all kinds of government demands to receive these subsidies. Research shows that patient organisations are satisfied with the opportunities to influence decision-making given to them by the government. The great majority of patient organisations comply with governmental demands without protest (P8).

Conclusion and discussion

Patient organisations today are quite different from the ones that were founded in the 1980s. Their organisational make-up, their activities and their input in decision-making have changed substantially. We have shown that these changes have been influenced if not brought about by the Dutch government. Government policy granted patient organisations an insider group status. Government policy directed at patient organisations has had a consistent focus over the years. Subsequent governments of different political colour have supported patient organisations so as to strengthen the position of patients and to transform them into a countervailing power to health care providers and insurers. This policy consistency can be explained by the fact that strengthening the position of patients is broadly considered to appeal to certain values such as self-development and democracy, examples of post material interests which many Dutch political parties support. This may apply less to the moderately conservative Christian Democratic Party which was part of government during most of this period, but then this party has always cherished civil society which may explain their ongoing interest in patient organisations. Thus supporting patient organisations fits nicely with widely shared values of different political parties. Furthermore, the fact that subsequent governments aimed to change the health care system into a more demand driven system during this entire period can also explain the continuous interest in patient organisations. The system based on regulated competition that was introduced in 2006 was the result of a reform process that had been on the

agenda for over 20 years (Helderman, Schut et al. 2005). Strengthening the position of patient organisations was and is seen as an important part of the reform process.

Although government itself at one point announced that it should practice restraint in influencing patient organisations (TK 16771 no.14, 22702 no.2) we conclude that its influence on patient organisations has been quite substantial. Of course it is widely acknowledged that the opportunity structure of civil society organisations is influenced by government. It can create incentives for them to behave in certain ways (Grant 1989; Nederland, Duyvendak et al. 2003). In this case however government influence is far reaching and does more than just create opportunities to influence decision-making in a certain way. Government successfully steered different aspects of patient organisations by subsidising and facilitating them. Most patient organisations seem to resign to the new procedures. The government has given them a position they can hardly refuse as they are given the opportunity to represent the interests of their members and their 'constituency' (people who suffer from a disease but did not join the patient organisation) in all kinds of decision-making processes. In order to reach this position they professionalise, they merge, they present a united front and they perform the administrative tasks required to apply for subsidy money. Many patient organisations even ask for more participation possibilities and more government subsidies to enable them to perform all the activities expected from them (Van de Bovenkamp, Trappenburg et al. 2010; Trappenburg 2008; Van de Bovenkamp, Grit et al. 2008a). They acknowledge that they are not an equal party in health care as the government would like them to be, and ask for more support to realise their full potential. Numerous intermediary organisations, researchers and members of parliament support this plea to increase participation possibilities and expand support for patient organisations. Most research into the current state of patient participation in the Netherlands concludes that the process is 'starting off', but that more opportunities should be created, more support should be granted and that patient organisations should professionalise further (see for instance Nederland and Duyvendak 2004; Oudenampsen, Kamphuis et al. 2008a; Van Wersch and Van de Akker 2005; Goudriaan and Goris 2007).

Although we sympathise with certain aspects of this evaluation, we feel that more attention should be paid to the disadvantages of governmental interference in civil society. We will therefore discuss both the positive and negative aspects in the following section.

The situation we described in our chapter has some positive effects for the different actors involved. A first positive aspect relates to the importance of *public accountability*. From a societal (taxpayer's) perspective, one may appreciate that government keeps a check on how public money is spent. Public accountability is an important

aspect of democratic governance; it is generally felt that government needs to be transparent about its decisions and its expenditures (Bovens 2005). Thus, it is important that patient organisations are transparent about how they spend public money.

Secondly, organising patient participation has proven a useful and successful *steering mechanism* for the Dutch government. It was part of their policy to strengthen the position of patients and reform the health care system into a demand driven system, with an aim to make it more effective and democratic. In such a system patients should behave like consumers who critically assess the care that is provided and who have a voice in decisions concerning their care. Patient organisations can play an important role in critically following health care, since it is felt that individual patients cannot do this alone. Strong patient organisations could be a countervailing power to the other parties on the health care market. It is also felt that strengthening patient organisations makes health care decision-making more democratic, since important stakeholders in health care are present at the decision-making table. Interestingly strong patient organisations could also cause problems for government should they oppose government policy. Nevertheless the government has repeatedly asked patient organisations to follow its own role critically. One might conclude that the government has created its own friendly opposition by subsidising and facilitating patient organisations, which may be a good thing from the government's perspective (although not necessarily from the patients' point of view). Patient organisations might feel free to follow the government critically (having been invited to do so after all), but the fact that they are not known to vehemently oppose the government (Trappenburg 2008; Nederland and Duyvendak 2003; Van de Bovenkamp, Grit et al. 2008a), could also be caused by this same policy. After all it seems harsh and less than polite to really bite the hand that feeds you. From a Machiavellistic perspective one may applaud this strategy as very effective.

The situation can also be valued as positive because it gives patients the opportunity to *influence health care decision-making*. Strengthening the position of patients in relation to health care providers, insurers and the pharmaceutical industry has been recognised as important in many countries (Baggott and Forster 2008; Grit, Van de Bovenkamp et al. 2008; Clarke, Newman et al. 2007). One of the means to do this is offering patient organisations the opportunity to speak on behalf of patients. Government policy in the Netherlands has given patient organisations access to all kinds of decision-making structures which otherwise would have been closed to them, or at least more difficult to conquer. Since one of the goals of patient organisations now is, albeit through government interference, representing the interests of their members, the participation possibilities facilitated by the government give them a means to accomplish their goal. Although patient organisations find it hard to really influence decision-making (Van de Bovenkamp, Trappenburg et al. 2010), thanks to

government facilitation patient organisations in the Netherlands now at least have the opportunity to voice their opinion on different subjects.

Another advantage is the *empowerment* of people who are active in these organisations. Participation is a way to increase their social capital (Van de Bovenkamp, Trappenburg et al. 2010; Trappenburg 2008). People otherwise left out in society are integrated and can participate in society again (ibid.). The active role of patient organisations therefore has positive effects on the individual level as well and can be part of a more general policy trend to create involved democratically skilled citizens (Clarke, Newman et al. 2007; Putnam 2000).

A last obvious advantage of government sponsorship is that this policy at least partly *prevents influence by the pharmaceutical industry*. Without government subsidies patient organisations would have to search for other financial sources and turning to the pharmaceutical industry for funds would then be a much more attractive option. This might leave the door open for patient organisations to be influenced by the industry. Sponsorship by the pharmaceutical industry is frowned upon both in the Netherlands and in other countries because of the danger of being influenced (Jones 2008; Bouma 2006; Lofgren 2004). Although the exact influence of industry on patient organisations is often not clear, and it is possible that their interests coincide, there is a lot of uneasiness about this relationship which can negatively affect the perception of the ability of patient organisations to speak for patients (Jones 2008). Therefore it may be important to avoid such ties.

Thus there are several reasons to evaluate the policy course in the Netherlands positively, particularly when we compare this situation to other countries. In comparison patient organisations are strongly embedded in decision-making structures in the Netherlands. However, there are also negative effects attached to Dutch government policy regarding patient organisations.

First of all the effect of *goal replacement* can be identified. Patient organisations have changed substantially over the years. Most of them were founded to provide peer support and information for fellow sufferers. At present an important part of the work of patient organisations consists of interest representation in formal decision-making structures. Whereas individual contacts with fellow sufferers were the primary focus before, at present patient representatives find themselves participating in all kinds of committees and project groups and producing papers to justify their expenses. Within these interest representation activities further changes can be identified. Whereas the original idea was that patients should improve the decision-making process by introducing their experiential knowledge, this is now pushed to the background due to the professionalisation of patient organisations (Van de Bovenkamp, Trappenburg et al. 2010). Professional staff members recruited by patient organisations now do

their very best to know whatever it is that the other parties at the bargaining table know also, be it medical technical stuff, economic insights or bargaining strategies. Although this enables them to talk to the other parties at the table, it raises important representativeness issues. Professional interest groups can diminish the democratic potential of such groups, since they distance themselves from the people they claim to represent (Skocpol 2003).

A second negative aspect is that the government's policy *ties the hands* of patient organisations. As was stated earlier it is difficult to criticise government policy when one receives government funding and has to meet all kinds of criteria attached to these subsidies. Their relationship with government puts patient organisations in a vulnerable position. It makes it more difficult for them to follow their own agenda and raise the issues patients really find important since they join existing structures. This applies especially when it concerns subjects that oppose government policy.

Thirdly patient organisations have become *policy and strategy followers* due to their institutionalised position. Institutionalisation diminishes the potential of protest (Grant 1989; Akkermans and Nobelen 1983). Because of all the possibilities to participate in formal decision-making processes opened up to them patient organisations are known to make little use of more oppositional strategies such as demonstrations and the use of the media (Trappenburg 2008; Nederland and Duyvendak 2004). They follow both the agenda and the strategies proposed by the government (Van de Bovenkamp, Trappenburg et al. 2010; Trappenburg 2008). Whether they are really able to influence decision-making in a neo-corporatist decision-making model can be questioned (ibid.). Nederland and Duyvendak show that relying on official institutional channels makes patient organisations less effective than they might otherwise be (Nederland and Duyvendak 2004).

Another negative effect is a *loss of empowerment*. Although patient organisations provide active members with an opportunity for empowerment and with a chance to increase their social capital, an effect which was also partly created because of government policy, the policy directed at professionalising these organisations may put this effect in jeopardy again. To be able to participate in all kinds of formal complicated decision-making procedures patient organisations now search for highly educated volunteers or professional employees, which means that not everybody can become active in a patient organisation anymore (Van de Bovenkamp, Trappenburg et al. 2010). The continuing government involvement and the additional government demands may undo the positive effect created by the initial government policy directed at patient organisations.

Lastly one may plausibly argue that patient organisations are *being put to instrumental use* by the government. Patient organisations are part of a governmental strategy to reach certain policy goals. The question is whether so much government

influence on civil society is desirable. Civil society organisations are considered important for democracy because they give citizens a means to let their voices be heard (Evers 1995; Couto 2001; Backman and Smith 2000; Warren 2003). It is argued that it is important for a viable democracy to maintain a balance in society between the state, civil society and the market (Zijderveld 1999). Too much government interference in civil society organisations may disrupt the balance.

Lessons for the future

So what can we learn from the Dutch situation? Government policy directed at patient organisations in the Netherlands has positive effects. It ensures public accountability, it provides the government with a successful steering mechanism, it offers patient organisations a chance to participate in health care decision-making, it opens up opportunities for empowerment for active members of patient organisations and it keeps patient organisations largely out of the hands of the pharmaceutical industry. All of this might be sufficient reason to consider a similar policy in other countries. The downsides of the Dutch model should also carry some weight though. Too much governmental steering may lead to goal displacement in patient organisations, ties their hands, makes patient organisations agenda and strategy followers rather than agenda setters, undoes the empowerment effect and may put patient organisations to instrumental use. These disadvantages tell every other government that considers this strategy (Baggott and Forster 2008; Leys, Reyntens et al. 2007) to proceed with caution. Of course no funding source is free of dilemmas (Jones 2008) and the fact that a policy has certain disadvantages does not necessarily have to lead to the conclusion that it should be abolished. When evaluating a certain policy it is also important to consider the alternatives. In this case the alternative would be that patient organisations would have far more difficulty in gaining access to certain decision-making processes. It would also leave them far more vulnerable to interference from the pharmaceutical industry. The situation in many other countries shows that patient organisations in the Netherlands are comparatively well off. Government interference may well be preferable if the alternative would be sponsorship by the pharmaceutical industry. However, we feel there is no need to simply accept the disadvantages of government sponsorship because the most obvious alternative would be far worse. We think that measures can be taken to improve the situation.

An important means to do this is the creation of a more independent financial source for patient organisations. Government might consider providing patient organisations with a basic subsidy that comes with fewer strings attached. Some broad criteria could be taken into account to ensure accountability for the spending of tax payers money, such as providing some insight into the activities and why they are relevant for their members. Making legislation that ensures this subsidy for a longer

period can further free patient organisations from too much government involvement. This way, patient organisations have more room to decide for themselves what they find important. They might decide to focus once more on the core tasks for which they were founded originally; peer support and providing information, the tasks many patient organisations themselves still consider to be most important (Oudenampsen, Nederland et al. 2007). Or they may decide to focus on contributing experiential knowledge in their participation activities instead of professionalising by familiarising themselves with the expertise of other parties. This might be quite difficult since patient organisations join long established decision-making processes which have certain modes of conduct. However, since listening to the patient's voice and valuing the patient's input is generally considered important in health care, this could be the way to accomplish just that. Patient organisations could also consider other influence strategies such as more activist ones instead of participating in formal decision-making procedures. Again it is important to consider the alternative; in the current situation there is access but this does not equal influence (Van de Bovenkamp, Trappenburg et al. 2010). It is therefore questionable whether the goals of more effective and democratic decision-making are reached in the current situation.

Such a policy of governmental restraint would mean that government would lose an effective steering mechanism. On the other hand subsidising civil society into obedience and compliance might be something a government in a democratic country should not be willing to do in the first place. Freedom of association is an important right in a democratic state, which can only be assured when government does not interfere with it too much. Although it is hard to pinpoint the exact boundaries to justified government assistance to civil society, practicing restraint for the sake of civil society's independence might do credit to the government (Trappenburg 2008).

Accompanying these decisions in policy practice we think it could also be worthwhile to pay scientific attention to ties between civil society and the state. This debate is important because, as stated before, our case study does not stand alone. A similar role for patient organisations is considered in other countries (Baggott and Forster 2008; Leys, Reyntents et al. 2007). Furthermore, similar ties between government and civil society exist in other policy sectors, for instance between government and ethnic minority organisations (Koopmans 2003; Rijkschroeff, Duyvendak et al. 2003). Another example is political parties which according to some have even moved from being part of civil society to being part of the state (Mair 2006). When these organisations are seen as important for a viable democracy because they offer groups a means to influence decision-making, they should be given the opportunity to play this role. Too much government influence can prevent them from doing so. It seems high time to start a debate on the limits to government interference in civil society.

Table 1 Overview of government policy documents analysed

| Year | Title | Code |
|------|---|------|
| 1981 | Nota Patiëntenbeleid (<i>White paper Patient Policy</i>) | G1 |
| 1983 | Voortgangsnota Patiëntenbeleid (<i>Follow up white paper Patient Policy</i>) | G2 |
| 1988 | Tweede voortgangsnota Patiëntenbeleid (<i>Second follow up white paper Patient Policy</i>) | G3 |
| 1988 | Financieel overzicht jeugdhulpverlening (<i>Financial overview youth care</i>) | G4 |
| 1992 | Nota Patiënten/Consumentenbeleid (<i>White paper Patient/Consumer policy</i>) | G5 |
| 1995 | Voortgangsbrief Nota Patiënten/Consumentenbeleid (<i>Follow up letter white paper Patient/Consumer policy</i>) | G6 |
| 1995 | Nota Volksgezondheidsbeleid 1995-1998 (<i>White paper Public health policy 1995-1998</i>) | G7 |
| 1997 | Jaaroverzicht Zorg 1998 (<i>Care overview 1998</i>) | G8 |
| 1997 | Vaststelling van de begroting van de uitgaven en de ontvangsten van het Ministerie van Volksgezondheid, Welzijn en Sport (XVI) voor het jaar 1998 (<i>Assessment of the budget of expenditures and receipts of the ministry of Health, Welfare and Sports for the year 1998</i>) | G9 |
| 1998 | Nota Marktwerking in de gezondheidszorg (<i>White paper Market based health care</i>) | G10 |
| 1998 | Vaststelling van de begroting van de uitgaven en de ontvangsten van het Ministerie van Volksgezondheid, Welzijn en Sport (XVI) voor het jaar 1999 (<i>Assessment of the budget of expenditures and receipts of the ministry of Health, Well-being and Sports for the year 1999</i>) | G11 |
| 2000 | Vaststelling van de begroting van de uitgaven en de ontvangsten van het Ministerie van Volksgezondheid, Welzijn en Sport (XVI) voor het jaar 2001 (<i>Assessment of the budget of expenditures and receipts of the ministry of Health, Well-being and Sports for the year 2001</i>) | G12 |
| 2000 | Vaststelling van de begroting van de uitgaven en de ontvangsten van het Ministerie van Volksgezondheid, Welzijn en Sport (XVI) voor het jaar 2001: voortgangsbrief over bundeling krachten patiënten en consumenten organisaties (<i>Assessment of the budget of expenditures and receipts of the ministry of Health, Well-being and Sports for the year 2001: follow up letter on combining the power of patient/consumer organisations</i>) | G13 |
| 2000 | Zorgnota 2001 (<i>White paper Care 2001</i>) | G14 |
| 2001 | Patiënten/consumentenbeleid: Met zorg kiezen De toerusting van patiënten en consumenten in een vraaggestuurde zorg (<i>White paper Patient/consumer policy: Choosing with Care: the equipment of patients and consumers in a demand driven care system</i>) | G15 |
| 2002 | Patiënten/consumentenbeleid: brief minister evaluatie en beleidsvoornemens over Fonds PGO (<i>Patient/consumer policy: letter of the minister on the evaluation and policy resolutions concerning the PGO-fund</i>) | G16 |
| 2004 | Patiënten/Consumentenbeleid: voortgangsbrief (<i>Patient/consumer policy follow up letter</i>) | G17 |

Table 1 Overview of government policy documents analysed (continued)

| Year | Title | Code |
|------|---|------|
| 2007 | Subsidiebeleid VWS, brief minister over de toekomstige financiering van PGO-organisaties (<i>White paper on subsidy policy of the ministry of Health, Well-being and Sports, letter on the future of financing patient organisations</i>) | G18 |
| 2007 | Verslag schriftelijk overleg over versterking pgo-organisaties: reactie van de minister (<i>Response of the minister of Health, Well-being and Sports to questions concerning the strengthening of patient organisations</i>) | G19 |
| 2008 | Subsidiebeleid VWS, brief minister over de toekomstige financiering van PGO-organisaties (<i>White paper on subsidy policy of the ministry of Health, Well-being and Sports, letter on the future of financing patient organisations</i>) | G20 |
| 2008 | Subsidiebeleid VWS, brief minister over de toekomstige financiering van PGO-organisaties (<i>White paper on subsidy policy of the ministry of Health, Well-being and Sports, follow up letter on the future of financing patient organisations</i>) | G21 |

Table 2 Overview of patient organisation research analysed

| Year | Authors | Title | Code |
|------|------------------------------|--|------|
| 1989 | Rijkschroeff | Ondersteuning van participatie in de geestelijke gezondheidszorg (<i>Participation support in mental health care</i>) | P1 |
| 2004 | Nederland and Duyvendak | De kunst van effectieve belangenbehartiging door de patiënten- en cliëntenbeweging. De praktijk (<i>The art of effective interest representation by the patient and client movement: Practice</i>) | P2 |
| 2004 | Klop, Kammen et al. | Patiënten doen mee bij ZonMw!. (<i>Patients participate at ZonMw!</i>) | P3 |
| 2004 | Van Veenendaal, Franx et al. | Patiëntenparticipatie in richtlijnontwikkeling (<i>Patient participation in guideline development</i>) | P4 |

Table 2 Overview of patient organisation research analysed (continued)

| Year | Authors | Title | Code |
|------|--------------------------------------|--|------|
| 2005 | Van Wersch and Van den Akker | Clïëntenparticipatie bij multidisciplinaire richtlijnontwikkeling in de GGZ: Ervaringskennis is geen kennis!?! (<i>Client participation in multidisciplinary guideline development in mental health care: Experiential knowledge is no knowledge!?!</i>) | P5 |
| 2005 | Caron-Flinterman | A new voice in science. Patient participation in decision-making on biomedical research | P6 |
| 2007 | Schut and De Bruijn | Collectieve zorgverzekeringen en risicoselectie (<i>Collective health insurance contracts and risk selection</i>) | P7 |
| 2008 | Trappenburg | Genoeg is genoeg. Over gezondheidszorg en democratie (<i>Enough is enough: on health care and democracy</i>) | P8 |
| 2008 | Oudenampsen, Kamphuis et al. | Patienten en Consumentenbeweging in Beeld: brancherapport 2007 (<i>A description of the Patient and Consumer movement: branchreport 2007</i>) | P9 |
| 2008 | Van de Bovenkamp, Grit et al. | Zaakwaarnemers van de patiënt (<i>Sponsors of the patient</i>) | P10 |
| 2008 | Van de Bovenkamp, Grit et al. | Inventarisatie patiëntenparticipatie in onderzoek, kwaliteit en beleid (<i>Inventarisation patient participation in research, quality policy and policy making</i>) | P11 |
| 2008 | Oudenampsen, Kamphuis et al. | Patienten en Consumentenbeweging in Beeld: brancherapport 2008 (<i>A description of the Patient and Consumer movement: branchreport 2008</i>) | P12 |
| 2009 | Sattoe | Belangenbehartiging belicht: een dubbelrol voor PGO-organisaties (<i>Interest representation: a double role for patient organisations</i>) | P13 |
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CHAPTER FOUR

PATIENT PARTICIPATION IN COLLECTIVE HEALTH CARE DECISION-MAKING: THE DUTCH MODEL

This chapter was published as:

Van de Bovenkamp H.M., M.J. Trappenburg, K.J. Grit (2010). Patient participation in collective health care decision making: the Dutch model. *Health Expectations*, 13 (1): p 73-85

Introduction

In modern health care, there is a strong emphasis on patient-centeredness (Bensing 2000; Grit, Van de Bovenkamp et al. 2008; Lewin, Skea et al. 2001). Although the patient was central in health care in the past, the patient was a less active participant than now. Currently, an active role is attributed to patients on both the individual and collective levels. One of the aspects of patient-centred care on the individual level is the expectation that patients become a partner of health care professionals, rather than finding themselves in a paternalistic relationship with them (Bensing 2000; Lewin, Skea et al. 2001; Gattellari, Butow et al. 2001; Guadagnoli and Ward 1998; Hibbard 2003; Joosten, DeFuentes-Merillas et al. 2008). Active participation of patients or health care users is also proposed for the collective level, even though representation of patients in health care decision-making can be said to take place through elected representatives (parliament, government) or through advocacy by experts (health care professionals) (Litva, Coast et al. 2002). Patients are represented in decision-making on various subjects, such as guideline development, research agenda setting, government policy-making and quality projects in institutions (Crawford, Rutter et al. 2002; Caron-Flinterman 2005; Trappenburg 2008; Van de Bovenkamp and Trappenburg 2009). The most important argument for active participation in health care decision-making on the collective level is that the experiential knowledge of patients supposedly improves the quality of the decisions. There are also other arguments in favour of participation, such as better implementation chances for chosen policies, increased legitimacy and accountability, democratic decision-making, patient empowerment and a more efficient and effective health care system (Grit, Van de Bovenkamp et al. 2008; Caron-Flinterman 2005; Van de Bovenkamp and Trappenburg 2009; Abma and Broerse 2007; Baker 2007; Boot, Telford et al. 2002; Epstein 2008; Hanley, Truesdale et al. 2001; Hewlett, De Wit et al. 2006; Hill, Fraser et al. 2001; Klop, Van Kammen et al. 2004). But how should participation in health care decision-making on the collective level be organised in practice?

There are three main ways to organise citizen participation. First, by inviting a representative group of average citizens to voice their opinion on a certain subject. Secondly, by asking a specific group of citizens, the ones that are affected by a certain decision, to participate. A third option is involving organised civil society groups. These different forms can be applied to the health care sector as well. In the Dutch case, there is a strong emphasis on the third option: patient organisations are often asked to represent the interests of patients in formal decision-making. This model can be described as neo-corporatist. The neo-corporatist model is often put opposite to a pluralist model of decision-making in which interest groups try to influence decision-making outside the system, especially by lobbying. In this chapter, we will study the patient participation approach in the Netherlands. We will answer

the following research question: *how does participation of organised patient groups in formal decision-making function in health care and what are the benefits and disadvantages of such a model?* This question is interesting for two reasons. First, patient participation in health care decision-making is on the agenda not only in the Netherlands but also internationally, and it is therefore important to learn more about effective ways to shape participation. Second, the Dutch case demonstrates how neo-corporatist decision-making functions in spheres other than that of socio-economic policy where the neo-corporatist model was first established.

Patients in the Netherlands have organised themselves at different levels. There are hundreds of disease-specific patient organisations, such as the breast cancer and epileptic associations. Individual patients can become members of these organisations. In the Netherlands, about half a million people have joined a disease-specific patient organisation (Oudenampsen, Kamphuis et al. 2008). These disease-specific patient organisations are members of larger umbrella organisations, such as the Dutch Federation of Cancer patient organisations and the Federation of Rheumatism organisations. These organisations work together in even larger regional and national umbrella organisations, such as the National Patient and Consumer Federation. In addition there are non-disease specific organisations catering to certain groups in society, such as organisations for elderly and psychiatric patients. Most of the work of patient organisations is carried out by volunteers. More than half of the disease-specific patient organisations work only with volunteers. Professionals support the work of the remaining disease specific organisations and the umbrella organisations (ibid.). Most (70%) patient organisations are associations, which means that they have an internal democratic structure in place; their members can give input and decide on the course of the organisations, mostly through general meetings. This is different in case of foundations, the organisational structure of the remainder of patient organisations, which do not have members but contributors which gives organisations more opportunities to decide on their course of action themselves (ibid.).

Interest groups depend on the opportunities the system gives them to influence decision-making. For instance, they need acceptance from other actors as a legitimate party before they can become part of formal decision-making procedures. The opportunity structure of Dutch patient organisations has been described as one in which the other actors are very open towards them (Nederland, Duyvendak et al. 2003). They are identified as a legitimate stakeholder and are asked to participate in many decision-making processes. This fits the neo-corporatist structure, or *polydermodel*, which can also be seen in other policy fields in the Netherlands (Woldendorp and Delsen 2008). The most important example is decision-making on social economic policy in which several unions and employer organisations have been

recognised by the Dutch government as legitimate partners in decision-making. Corporatist decision-making structures exist in other sectors as well, for instance, the environmental movement is part of formal decision-making on environmental policy (Huiteima 2005). The patient organisation case, however, is quite distinctive, given that there is no formal selection of organisations that can participate. All patient organisations that wish to, may participate in decision-making processes. Patient organisations are recognised by the state and are called the third party in health care next to providers and insurers. Due to this recognition, patient organisations are increasingly asked to participate in decision-making processes. Moreover, patient organisations are heavily subsidised, enabling them to play this active role (TK16771 no.31, TK29214 no.24, 28). Additionally, patient organisations have the opportunity to influence decision-making from the outside through lobbying, much like any interest group in a democratic state.

In other countries, the situation is different. Patients, health care consumers and disabled persons have organised themselves and tried to influence policy in varying degrees (Baggott, Allsop et al. 2005; Van der Zeijden 2000; Wilson 1999, Rodwin 1994; Allsop, Jones et al. 2004; Bagott and Forster 2008; Wood 2000; Lofgren 2004). However, the invitation to participate in formal decision-making seems less automatic than is the case in the Netherlands. Patient organisations are just one of the possible participants amongst others, such as the public, unorganised patients and carers (Hanley, Truesdale et al. 2001; Florin and Dixon 2004; Wright, Parry et al. 2005; Callaghan and Wistow 2006; Lester, Tait et al. 2006; Maxwell, Rosell et al. 2003). Governments in other countries are also less supportive of patient organisations (Baggott, Allsop et al. 2005; Wilson 1999; Wood 2000).

In this study, we first describe the methods used to study the situation in the Netherlands. In the Results section, we then describe: the participation opportunities, the influence patient organisations can exert on policy and the effects on patient organisations themselves. In the Discussion, we focus on several dilemmas attached to this model. We will show that the opportunity structure is simultaneously both enabling and constraining.

Methods

For the empirical part of our study, we conducted 52 interviews with different actors in the Dutch health care field. First, we interviewed representatives of patient organisations (n=35). We selected patient organisations from the different layers of the patient movement and aimed to have a mix in both size of the organisation (large, medium and small organisations), and background of representatives (active volunteers and professional employees). By selecting organisations according to these different criteria, we tried to gain insight in differences between organisations' ability to participate and the

dynamics between the different layers of the patient movement.

Additionally, we interviewed other actors in the Dutch health care field who have had experiences with patient participation in decision-making processes. These actors were identified through a document study (Van de Bovenkamp, Grit et al. 2008) on which type of actors have contacts with patient organisations. We selected representatives of different actor groups: the ministry of health (n=2), supervisory bodies (n=2), health care providers (n=2), health care insurers (n=3), intermediary organisations⁸ (n=4), research institutions (n=2), a health fund (n=1) and a government advisory body (n=1). An overview of the organisations we interviewed is given in Table 1.

We asked the respondents of patient organisations about their participation activities. How were they active, what were the experiences with these activities in terms of influence and what were the consequences for patient organisations? We asked the other respondents about their experiences in dealing with patient organisations in decision-making. How were patient representatives given the opportunity to participate, were they able to participate, how did they contribute and in what way would these actors like to continue with patient participation in their future decision-making?

The interviews were recorded and fully transcribed. In the analysis, we used the following analytical schemes: (1) what does the opportunity structure look like (what subjects allow for participation and how can organisations be active); (2) what are the related experiences; (3) what was the patient organisation's input and influence on policy-making; and (4) what are the effects on patient organisations (what kind of conditions must they meet and how do they deal with their role)?

⁸ Organisations that function as intermediaries between different actors in health care, such as the Dutch Institute of Healthcare Improvement, which brings different healthcare institutions, professionals, patients and researchers together to work on the improvement of health care.

Table 1 Organisations interviewed

- NZa, the Dutch Healthcare Authority
 - IGZ, the Dutch Health Care Inspectorate
 - Slingeland, hospital
 - Atrium, hospital
 - Ministry of Health Welfare and Sport (2x)
 - De Friesland, health insurance company
 - Univé, health insurance company
 - Miletus, joint initiative of health insurance companies to measure the experiences of patients
 - CKZ, centre that coordinates the development and implementation of the Consumer Quality index
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Table 1 Organisations interviewed (continued)

- CBO, Dutch Institute for Health care Improvement
- STG, Dutch network for research, strategy development and health care innovation
- RIVM, the National Institute for Public Health and the Environment
- NIVEL, the Netherlands Institute for Health Services Research
- MEE Nederland, national organisation of MEE organisations (organisations that support people with a handicap or chronic illness)
- Heart foundation
- HOB, organisation that provides support to patient organisations
- Per Saldo, organisation of people with a health care budget to be spent on services of their choice
- DVN, Dutch diabetes association
- BVN, Dutch breast cancer association (2x)
- Lymph node cancer association
- VSN, Dutch association for muscular diseases
- Pandora, organisation of mental health patients
- Alzheimer Netherlands
- Dutch scoliosis association
- Friedrich Wegener foundation, organisation of patients with vasculitis
- ME/CVS foundation
- Parkinson patient association
- ANBO, elderly organisation of people over 50
- Child and Hospital
- EVN, Dutch epileptic association
- Dutch Oscar foundation, organisation of patients suffering from sickle cell anaemia
- Clientenbond, organisation of mental health patients
- LNKO, national network of critical parents of handicapped children
- Balans, organisation of parents of ADHD patients
- Pancreas association
- Ypsilon, organisation of family members of patients who suffer from psychosis
- NFK, Dutch federation of cancer patient organisations
- Federation complementary care
- SHHV, foundation dealing with diseases in head heart and blood vessels
- Federation of rheumatism organisations
- CSO, central association of elderly organisations
- CG-raad, chronically ill and handicapped council, national umbrella organisation
- Consumentenbond, national consumer organisation
- NPCF, National Patient and Consumer Federation, national umbrella organisation
- LOC, national organisation of client councils of elderly institutions and home care
- LSR, national organisation of client councils of hospitals, and intramural care institutions
- LPR, national organisation of mental health client councils
- Clientenbelang Utrecht, regional client umbrella organisation
- Zorgbelang Friesland, regional client umbrella organisation

Results

Participation possibilities

Participation by patient organisations is not just a policy proposal; it is also put into practice. According to respondents (n=17), the time is right for patient organisations because it has become “fashionable” to involve them:

These days it is not done to say that you find it a senseless development. (respondent Per Saldo)

Thirty or so years ago, the situation was quite different. Our respondent from the breast cancer association recalls that volunteers who tried to provide peer support were not at all welcomed by the hospital staff. These days, however, the other parties involved in health care decision-making, government, providers, insurers and researchers, give patient organisations many opportunities to participate. On the basis of our interviews, we can report the following participation possibilities.

Patient organisations are consulted by the ministry of Health Welfare and Sport, parliament, government supervisory and advisory bodies and municipalities. Some patient organisations also try to influence economic and social policy in addition to health care policy, by consulting with these ministries and contacts with MPs.

Participation by patient organisations can also influence health care providers. They contribute the patient perspective in guideline development groups and participate in the development of indicators used by the Dutch Healthcare Inspectorate. Some patient organisations develop their own quality criteria and attribute quality marks to providers who then provide care according to these criteria. Furthermore, they are involved in health care improvement projects and in the training of professionals. Smaller organisations sometimes focus more on representing the interests of individual members and intervene when they feel that one of their members is not receiving the appropriate care.

As the introduction of the Health Insurance Act, the activities of patient organisations have expanded. With the introduction of this act, a system of regulated competition was introduced in Dutch health care. In a system where insurers compete to provide insurance, patient organisation-insurer contacts are potentially interesting for both parties. Patient organisations can negotiate collective contracts for their members, both on the content and price of insurance packages that are complementary to the basic package and can thus provide insurers with more clients. They also provide insurers with information for health care purchasing, which insurers can use in their contract negotiations with health care providers. Health care insurers, health care providers and patients, have also worked together to develop and imple-

ment the Consumer Quality Index.⁹

Patient organisations are also active in decision-making on health research in different ways. They can play an intermediary role between researchers and patients that are needed as research subjects. They are increasingly consulted in the development of research agendas and in research proposal assessment and supervisory committees.

The opportunity structure is one in which Dutch patient organisations can become part of institutionalised formal decision-making on different levels, which affects the chosen strategy of influence. There is a strong focus on participation in formal decision-making processes and consultation, where the different parties in health care try to establish consensus. The importance of this is also recognised by the other parties in health care (n=5). An insurer claims:

So we [insurer and regional patient umbrella organisation] are talking, we do not judge each other and we keep looking for possibilities to create an understanding for the other's point of view and to make improvements where possible. (respondent de Friesland)

In addition many patient organisations (n=25) report on lobbying activities outside the formal decision-making processes, mostly directed at the government and political parties. Most of this lobbying consists of writing letters and consultation; sometimes the media are also used. Mostly patient organisations are not looking for confrontation, however. Only one patient organisation, the Diabetes association, had recently chosen a more oppositional strategy, trying to shake things up with harsh comments, e.g. saying that the quality of care is insufficient. Although other respondents identify diabetes care as a best practice that they would like to follow for other conditions, the Diabetes association strategically argues that diabetes care leaves much to be desired. This new proactive strategy leads to a situation in which patient representatives vent their troubles without much nuance but according to our respondent this is part of a transition towards a situation with a stronger position of the patient.

I am well aware that patients reach a point where they just cry out what they're feeling, without worrying about the consequences. The same thing happened in communist revolutions – people were victimised there too, you know. But the point is, voicing one's feelings accomplished something. (respondent Diabetes Association)

⁹ An instrument that measures patient experiences with health care.

Most patient organisations focus on the consensual mode of participation in formal decision-making arenas. When patient organisations focus on formal decision-making processes and abstract policy issues, they become part of the formal decision-making structure and become institutionalised. Through this institutionalisation, they have the opportunity to act on all of the subjects mentioned. It has become an accepted practice to involve them, although most organisations want even more opportunities for participation and structural involvement (n=26). Many of the other actors wish to increase their contacts with patient organisations as well (n=9). Interestingly, at the same time, many patient organisations identify overload as a problem (n=26); they are asked to participate in so many cases that they cannot comply with all the requests.

You are swamped with stuff. It is too crazy for words, so many opportunities to participate. (respondent Pancreas association)

This difficulty in complying with all requests is intensified by the fact that patient organisations have difficulty in finding volunteers. They must deal with the fact that volunteers have to drop out regularly because of their illness. This leads to a situation in which a lot of work is carried out by a couple of active members.¹⁰ So, even though organisations may want to do more, for practical reasons, this is not always possible. They must look for (collective) solutions that increase their effectiveness as an organisation.

Many patient organisations (n=29) therefore emphasised the need to work together to strengthen their position and to cope with all the participation opportunities given to them, although they acknowledged that they do not do this often enough in practice. Other parties (n=5) also emphasise that they prefer united patient organisations, because it is more convenient for them to talk to one central organisation. The layered configuration of the patient movement in the Netherlands can arguably be seen as an organisational response to this situation. It offers patient organisations a chance to work together and be active on different levels of decision-making:

Here's how we see it. Interests that all patients have in common, regardless of their condition, are taken up by the National Patient and Consumer Federation. Common interests of people with cancer are dealt with by the Dutch Federation of Cancer patient organisations. And when it concerns the specific interests of women with breast cancer, men with prostate cancer or whatever, then this disease specific organisation becomes active. (respondent Dutch Federation of Cancer patient organisations)

¹⁰ One respondent calculated that she spent 3250 h a year working for her organisation on a volunteer basis.

However, this division of tasks is not easy. The members of the umbrella organisations do not always agree with the chosen course. And there is a difference of opinion on which activities member organisations should perform and which should be performed by umbrella organisations. Some respondents (n=9) feel that disease-specific organisations put too much emphasis on their individuality and the differences between groups of patients.

It surprises me that almost all patient organisations I have talked to (...) complain about a shortage of money and board members, but when you respond by telling them to work together, because then you need fewer people and can spend your money more efficiently: no. It is the uniqueness, you know: "They will lose their uniqueness". (respondent Federation of Complementary Care)

Another strategy used by patient organisations to cope with overload is prioritising. Some see the need to delineate the issues that they feel are important and should be pursued. By attaching criteria to their decision to participate or not (n=21), they can be selective and not pursue every subject that comes up.

Influence

One of the goals of patient organisations is to influence decision-making, which we saw in several cases. The HIV and the breast cancer associations, for example, were both able to change policy concerning medication distribution, while Per Saldo, an organisation for people with a personal health care budget, was able to change the reimbursement criteria of health insurers. Several patient organisations (n=5) involved in a health care purchase project of an insurer were positive about this opportunity and claimed that their participation had led to positive outcomes, such as interdisciplinary teams and more information for patients. The association for muscular diseases is very successful as a driving force in research and treatment guidelines. The organisation for children in hospitals created a quality mark, which insurers now take into account in their negotiations with hospitals, resulting in hospitals making changes to deliver care according to these criteria. The Diabetes association contacted the media to draw attention to unsafe blood tests, which led to an increased use of protocols. *Clientenbelang Utrecht*, a regional umbrella organisation, signalled problems concerning dental care and now works together with the professional organisation of dentists on guidelines for improvement. The National Patient and Consumer Federation (NPCF) and the *Consumentenbond* made it easier for patients to file complaints and the NPCF also successfully lobbied for a health care consumer act, which is currently being developed.

Interestingly however, successful influence does not always result from partici-

pation in formal decision-making processes. The aforementioned changes of cancer and HIV drugs policy, attention for the diabetes protocols and the dentist guidelines, for example, all resulted from other strategies: using the media and lobbying.

Despite their successes, patient organisations question their ability to influence decision-making in a general sense. They also report on examples of unsuccessful attempts to enhance policy outcomes (n=18). Negotiating collective contracts with insurers is an example of this:

The insurer says: "we will do it like this", and that's it. (respondent HIV association)

Patient organisations attribute their lack of success to their dependent position (n=25), which is also recognised by other actors (n=5). Other actors in health policy-making do not really need them; they can make their decisions and policy without them if they want to.

We [a regional patient umbrella organisation] are often dependent on the goodwill of health care providers, municipalities or the insurer. They have to acknowledge the importance of involving the patient movement. If they don't they would get away with it. Because they are not obligated to make decisions together. They could do it without us. So it is terribly nice and kind and we are very glad with such a covenant [with the regional insurer] but it depends on goodwill. If the insurer would say: "Enough. We won't do it anymore", there's nothing we can do about it. (respondent Zorgbelang Fryslan)

Moreover, because of their institutionalised and dependent position, it becomes difficult for patient organisations to follow their own course. They are in danger of being put to instrumental use as our respondents from both groups note (n=17). They are asked to contribute their opinions on items decided on by other parties, and it is questionable whether they can really influence the process. One respondent even feels that participation for many patient organisations has become a goal in itself:

There are quite a few organisations that find it marvellous to sit at the table with all these different parties; with the secretary of state for instance. I mean that is so pompous. (...) I think most of these organisations absolutely lose sight of what it is all about, and what life is about when you are unlucky enough to get some rotten disease anyway. (respondent Pandora)

Patient organisations are asked to contribute 'the patient perspective' to decision-

making. Although this experiential knowledge base is not questioned by the different actors we interviewed, representatives of patient organisations do report on not being taken seriously in practice. Four of them directly link this to the difficulty of getting their experiential knowledge across:

When you've got one experiential expert in a guideline committee, you can say something a hundred times but that doesn't get acknowledged (...). But afterwards the outcome will be marked 'client approved'. So the question is, is it wise to participate in such a committee at all? (respondent Pandora)

The representativeness of input from patient organisations is occasionally questioned by other parties (n=2). According to our respondent from the organisation in charge of the government website kiesbeter.nl¹¹:

And what I am thinking about now is the difference between what you hear from patient organisations about what people want to know, (...) and what an average individual wants to know. (respondent RIVM)

That other actors also question their representativeness is suggested by the fact that organisations seeking the input of patients do not merely want to talk to representatives of patient organisations but want to consult unorganised patients as well. They consider additional participation methods (n=10), to learn more about what patients want or think about a subject.

Effects on patient organisations

Representatives of patient organisations report a positive effect of participation on the wellbeing of those who participate. Participation can be a means for patients to feel useful again, learn new things and increase their social capital (n=8). Some patients are no longer capable of work, but can be active in their patient organisation:

When I think of a member of our board (...) he used to be a manager in a shop and he suffered from low self esteem because he was declared unfit to work, a very miserable situation. And then there you are; no job, pancreas patient (...). But that guy is now working here and he feels like somebody again. So it also serves a very important purpose for the volunteers. (respondent Pancreas association)

¹¹ kiesbeter.nl is a government-funded website intended to assist patients in choosing their healthcare provider and their healthcare insurer.

Professionalisation is often claimed to be necessary to be able to participate, both by patient organisations themselves as by other actors in health care (n=34).

When the other party can rely on [your professionalism] (...) it becomes easier and easier to convince that other party. And that is how it works and we have that kind of position now. (respondent Per Saldo)

Professionalisation programmes primarily target volunteers. Participation in formal structures is not an easy task and requires much time. According to our respondents, many volunteers lack the knowledge to be able to contribute. The first requirement, often mentioned, is that patient representatives are able to look beyond their own experiences. They further need to have strong negotiating skills or an understanding of medical or scientific knowledge, both of which can be used during discussions with other actors. Moreover, they must be able to express themselves and be heard. To be able to meet these requirements, volunteers receive training from their patient organisation and/or organisations that organise patient participation in decision-making. Despite claims that such professionalisation is a prerequisite for participation, the whole practice raises questions concerning volunteers' actual representativeness once they have different knowledge and abilities than the average patient. Training of volunteers can contribute to their empowerment process, but part of the professionalisation is also a search for 'the right volunteers' who already possess many skills mentioned above. Not everyone can thus become active in a patient organisation, which diminishes the empowerment potential for certain groups of patients.

The empowerment effect cannot occur at all if patient organisations decide to employ healthy professional workers. Yet, it is claimed that active volunteers with experiential knowledge are not enough for patient organisations to be successful. Although they have the experiential knowledge that is continuously emphasised as imperative, respondents point out the need for professional employees who have the knowledge to influence decision-making and to safeguard the continuity of the organisation (n=25). To be able to participate, skills are necessary that volunteers just do not have:

Too many interests are at stake and it becomes too serious to ask that from a volunteer. (respondent Child and Hospital)

Working with professionals further increases the aforementioned concerns regarding representativeness. Although many respondents acknowledge that this professionalisation process is difficult, only a few respondents (n=3) resisted the

professionalisation idea and the pressure to become more active in formal decision-making processes.

Discussion

One characteristic of neo-corporatism is that actors need to be recognised by the government to become part of the formal decision-making structure. Government therefore decides who is in and who is out (Akkermans and Nobelen 1983, Cawson 1986, Williamson 1989). In this case, we find a similar situation, though shaped differently.¹² Patient organisations have become part of the decision-making structure, but there are too many opportunities for participation and many organisations simply cannot cope with the demand. Although the opportunity structure does not deny access, it can still inhibit participation because it demands so much time and energy that many organisations fail to meet expectations. Some organisations are unable to have a consistent presence simply because of decreases in population; lung cancer is one example. Organisations representing patients with less debilitating diseases may be much better at participating. Furthermore, some patient organisations, mostly those representing large patient groups, have the funds to professionalise, whereas others do not. As was reported in the more pluralistic model in the USA where patient organisations lobby for research into their particular disease (Callahan 2003, Dresser 1999, Resnik 2001), this could lead to redistribution effects, also in the neo-corporatist structure of the Netherlands.

In a neo-corporatist structure, influence is also an issue. Participants are seeking consensus and must often be satisfied with less-than-ideal outcomes (Akkermans and Nobelen 1983). This problem is intensified because of the difficult fit between patient organisations and the formal decision-making structure. Patient organisations have difficulty in contributing their perspective and have little bargaining power to support their position. However, for a neo-corporatist structure to work, some kind of power symmetry between the involved parties is necessary (Held 2006). Given the fact that patient organisations do not have an equally powerful position as the other longer-established powerful parties in health care, this case shows that participation does not equal influence. The position of patient organisations is legitimised by the contribution of their experiential knowledge. However, part of the difficulty is that this knowledge alone is insufficient. They also need the capacities to get their points across in decision-making procedures with professional partners who have a strong knowledge base of their own. Experiential knowledge seems to be valued

¹² Despite market reforms, introduced in 2006, the Dutch government still plays a very important role in healthcare politics. It has promoted patient organisations since the 1980s and has continued to do so ever since.

less than the evidence-based knowledge of health care professionals. Additionally, patient organisations have little power to force other parties to listen to them. Because they must first seek legitimacy, patient organisations begin in a dependent position, which leads to the possibility that their inclusion will merely be instrumental. Patients are asked to participate but cannot really influence the process, while the other parties can point to their presence at the table and say that they support the decisions made. Harrison and Mort (1998) refer to this as playing the user card. If patients refuse to cooperate or have a different opinion, their opinion can easily be overridden and the other parties can continue without them.¹³ This dependent position also makes it difficult for patient organisations to follow their own course; they seem to follow the agenda of other parties instead. It is not clear whether participation in formal decision-making accomplishes more than trying to influence decisions from the outside. Indeed, several of the successful examples of patient organisations influencing health policy came from lobbying (see also Nederland and Duyvendak 2004).¹⁴ The question therefore becomes whether this neo-corporatist model is a good model to influence decision-making or if patient organisations should look for other ways to influence policy-making.

Finally, the effects on the organisations themselves raise some problems. An important issue often mentioned in the literature is the representativeness and accountability of interest groups (Halpin 2006, Phillips 2006). Participating in formal decision-making is not an easy task and the reaction of patient organisations has been to professionalise. Tasks previously carried out by volunteers are now performed by professional workers, or by trained, mostly highly educated, volunteers (see also Trappenburg 2008, Nederland and Duyvendak 2004, Oudenampsen 1999, Verkaar 1991). Although professionalisation is necessary to be able to contribute, it simultaneously creates distance between active participants and those they claim to represent. Professional employees and professional volunteers have different knowledge that could colour their input and that brings the issue of representativeness to the fore. The experiential knowledge patients were originally asked to contribute could paradoxically disappear in the background this way. Professionalised interest groups diminish the democratic potential of citizen groups (Skocpol 2003). Whereas citizen groups with strong roots in society can strengthen democracy because ordinary people are mobilised, can participate, gain skills and interact with different people (Skocpol 2003, Putnam 2000), professional groups often lack such

¹³ Harrison and Mort studied patient panels in the NHS, indicating that the danger of instrumental use is not limited to formal decision-making structures as discussed here.

¹⁴ It is likely, however, that patient organisations can be successful in such lobbies in the Netherlands, partly as a result of their acknowledged position.

ties and therefore their contribution to democracy can be questioned. When patient organisations focus on their professionalisation too much, they move away from the people they represent, which negatively affects their democratic potential. Another side-effect of the continuous emphasis on professionalisation and the search for the 'right volunteers' is that the empowerment effect (Bate and Robert 2006) that patient organisations can have for their members is in danger of disappearing.

We feel the results of this study are not relevant only to the Dutch case, as a similar role for patient organisations is being developed or considered in other countries (Baggott, Allsop et al. 2005, Baggott and Forster 2008, Lofgren 2004, Leys, Reyntens et al. 2007, Jones 2008). We argue that the opportunity structure created in the Netherlands to make patient organisations an equal third party in health care does not accomplish this goal in practice. It is important to look critically at this mode of participation and its effects. The problem of the number of participation possibilities is that there are too many, not too few. It is therefore important to investigate further which subjects lend themselves to patient participation and which ones do not. The idea that patients should become an equal third party in every decision-making process concerning health care is not feasible in practice nor is it desirable when we look at the effects described in this study. It is also important to study other influence strategies of patient organisations such as lobbying or media utilisation. Forms of participation that rely on individual patients, such as focus groups, shadowing and training by patients (Bate and Robert 2006, De Wit, Mul et al. 2008, Van Hooff and Bocharde 2007) which have the advantage that they demand less of participants and are able to stay close to patient experiences, should also be considered.

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CHAPTER FIVE

THE RELATIONSHIP BETWEEN MENTAL HEALTH WORKERS AND FAMILY MEMBERS

This chapter was published as:

Van de Bovenkamp H.M., M.J. Trappenburg (2010). The relationship between mental health workers and family members. *Patient Education and Counseling*, 80: p. 120-125

Introduction

Informal care such as traditionally provided by family members or close friends has become an important subject on the policy agenda of many Western countries (Bittman, Fast et al. 2004). Family members are expected to care for their sick family members or relatives with disability and many of them do (Timmermans 2003). In mental health care informal care is also very important. Because of the policy of deinstitutionalisation in this sector family members have to take on more caring tasks than before (Peternelj-Taylor and Hartley 1993; Laidlaw, Falloon et al. 1999; Ostman, Hansson et al. 2000; Boye, Bentsen et al. 2001; Dutch schizophrenia guideline 2005; Cheng and Chan 2005; Gutierrez-Maldonado, Casqueo-Urizar et al. 2005). They can assist in the diagnostic process and take on several caring tasks (Gasque-Carter and Curlee 1999; Marsh 1999; Cheng and Chan 2005; Sin, Moone et al. 2005; Clearly, Hunt et al. 2006; Van de Bovenkamp and Trappenburg 2008). Since mental illnesses can be unpredictable - patients who become psychotic, threaten to kill themselves or wander the streets at night - family members also have to deal with crisis situations (Karp 2001; Van de Bovenkamp and Trappenburg 2008). The fact that mental health care patients do not always acknowledge that they are ill and the subsequent difficulty in finding professional help for the patient, further complicates matters for family members of mental health patients compared to family members of relatives with a somatic condition (ibid.).

The literature shows that the active role of family members can have positive effects on patients (Glick, Clarkin et al. 1993; Gezondheidsraad 1999; McFarlane, Dushay et al. 2000; Dutch schizophrenia guideline 2005). Their activities may also provide significant cost benefit to government where the alternative would be greater requirement for paid services. The active role of family members of mental health care patients fits into the broader trend of active citizenship: of giving citizens more responsibilities to solve societal problems. One of these responsibilities is to care for each other, to be able to accommodate the increase in the demand of health care and to control health care costs (Tonkens 2006). However, Tonkens argues that citizens need support in order to be able to play that role. If people are simply expected to become active they may not be up to the task or suffer from problems of overload (ibid.). The fact that the burden of care for family members of mental health care patients is high has been amply discussed in the literature (Peternelj-Taylor and Hartley 1993; Gasque-Carter and Curlee 1999; Laidlaw, Falloon et al. 1999; Magliano, Fadden et al. 1999; Ostman, Hansson et al. 2000; Chang and Chan 2005; Sin, Moone et al. 2005; Gutierrez-Maldonado, Casqueo-Urizar et al. 2005; Harden 2005; Magliano, Fiorollo et al. 2005; Clearly, Hunt et al. 2006). The effects can be substantial and include reduction of social contacts and social life, less time for themselves, revision of career and retirement possibilities, changing family relationships, feelings of guilt,

stress and grief (Peternelj-Taylor and Hartley 1993; Rose 1997; Laidlaw, Falloon et al. 1999; Gasque-Carter and Curlee 1999; Marsh 1999; Ostman, Hansson et al. 2000; Karp 2001; Stuening, Perlick et al. 2001; Marshall and Solomon 2004; Gutierrez-Maldonado, Casqueo-Urizar et al. 2005; Sin, Moone et al. 2005; Harden 2005; Magliano, Fiorillo et al. 2005; Clearly, Hunt et al. 2006; Legatt 2007; Van de Bovenkamp and Trappenburg 2008).

To enable family members to play their active role and to limit the negative effects of caring, family members need support. Professional mental health care workers may be an important source for support, since they are acquainted with psychiatric diseases and therapeutic possibilities in general, they know the patient and they probably meet his or her family members on a regular basis. Thus, it is important to pay attention to the relationship between family members and mental health care workers to see whether they do indeed support family members so as to enable them to play their active role. In this study we explore the ways in which family members experience their contacts with mental health care professionals.

Methods

The study was conducted using a multi-method design. Such a design enables researchers to compare different data, thus allowing for cross-fertilisation and triangulation. On the one hand one may get ideas and information from one method which one would not have acquired by other methods. On the other hand one can use the multi-method approach to check whether data collected by one method (say by interviews) can also be witnessed if one uses another method (say observation) (Brewer and Hunter 2005). In order to maximise the chances of cross-fertilisation we used two research methods simultaneously, viz. semi-structured interviews and observation. We conducted semi-structured interviews with 18 family members of mental health patients in the Netherlands. Our interviewees included parents, siblings, partners and a daughter of a patient, all of them family members of patients with severe and long-term conditions (most often schizophrenia, sometimes with an additional diagnosis of autism, or an eating disorder, in two cases manic depression and in three cases the diagnosis remained unclear even though the patients had been in contact with the mental health care sector for a long time). The family members we interviewed were all actively involved with the patient. Respondents were contacted through Ypsilon, an organisation for family members of patients with schizophrenia and psychotic episodes (n=14) and through the family council of a mental health hospital in the Netherlands (n=4). We worked with a topic list in order to ensure that core areas were covered but respondents were given the opportunity to relate their individual stories. Our topic list was composed after a literature search on the subject of family members in mental health care. The topic list

consisted of some general background questions such as the relation to the patient, the diagnosis of the patient, the medical (psychiatric) care the patient was currently receiving and how much contact there was with the patient. We further asked what kind of care family members provided for the patient and how having a severely afflicted mental health patient as a family member affected their own lives. We then asked about their experiences with professional mental health care workers: how did they communicate with them about the patient and did they receive support from them. The interviews were recorded on tape and fully transcribed, except for two on the respondents' request. In these two cases extensive notes were taken by the interviewer at the time of the interview.

In addition, we interviewed other parties involved in the care of mental health patients: a mental health patient, who sat on a patient council of a mental health hospital, a patient who was active in a patient organisation, two social workers, four psychiatric nurses and the assistant of the family council, to probe their feelings and ideas on the contacts between family members and professionals.

During the same period we performed observations at a long-term care ward of a mental hospital during 1 week, and we observed four meetings of the hospital's family council and two meetings of the client council. During these observations extensive notes were taken by the researcher concerning family contacts and the experiences with and opinions of health care workers and family and client council members concerning this subject.

We performed a content analysis on the interviews and observations. Two researchers independently analysed the interviews and the observation notes. After seven interviews a preliminary analytical scheme was composed, which was refined after analysing the other interviews. We analysed the data on the following subjects: (1) carer activities, (2) effects of carer activities, (3) receiving information from professionals, (4) providing information to professionals, (5) consultation with professionals about the care of the patient and (6) support needed and provided.

To accomplish further triangulation we presented our preliminary findings at an Ypsilon conference at which family members were present, at a schizophrenia conference for mental health care workers and at a symposium of a mental health care institution where both family members and mental health care workers were present. In addition we sent our preliminary research report to Ypsilon and a mental health hospital for comments. If either of these audiences would have informed us that our findings were incorrect, one-sided or biased according to their own experience, we would have searched for additional data (more interviews and more observations). However, the conference audiences as well as our contacts at Ypsilon and the mental health hospital informed us that our findings looked very plausible and familiar to them.

This type of research does not require consent from an ethics committee in the Netherlands. We asked our respondents permission to use quotations from their interviews, on the basis of anonymity, to which all of them agreed.

Results

In this section we will first describe the caring activities of family members. We will subsequently describe the experiences of family members with their contacts with mental health workers. An overview of the experiences of our respondents concerning their contacts with mental health care professionals can be found in Table 1.

Caring for a family member suffering from a psychiatric condition

All of the family members we interviewed (n=18) performed carer activities. Family members report that they are often the ones to notice that there is something wrong, that their family member needs help and try to convince their family member to find this help. At a later stage they take care of the patient's finances, perform domestic tasks, provide daytime activities and check the patient's medication. Moreover many respondents (n=16) report having to deal with their family member who engages in dangerous behaviour (wandering the streets at night) or exhibits suicidal behaviour. Family members also try to represent the interests of the patient when the patient cannot (temporarily) do this (n=17), they help to formulate his or her care needs for instance. According to one of our respondents, things would have ended badly for her husband if she would not have done so:

I fear for people who do not have this support from their family, in case of my husband: he could have been dead now, or vegetating in a nursing home or something, [without me] he would have ended it himself. (wife of husband with a psychiatric condition)

In addition to taking care of the patient family members report of worrying about the patient (n=17), about the care he/she receives, about his/her future, but also about themselves and the rest of their family. Family members talk about a mourning process whereby they have to say goodbye to the family member they knew and get another family member in return. This also affects the relationship they have with the patient. Furthermore, family members often experience physical or mental problems due to their caring activities (n=15).

Given all these caring activities and their effects, contacts between professional mental health workers and family members are important, both for the patient and for the relatives, to be able to effectively care for the patient and to learn how to

Table 1 Contacts with professional mental health care workers

| Respondent | Experiences with mental health care professionals |
|--|--|
| 1. Mother of a stepson with a double diagnosis (psychiatric disorder and drug addiction) | Very bad, lack of information sharing and consultation. Has filed several formal complaints. |
| 2. Husband of a wife with manic-depressive illness | Very bad in the past, lack of information sharing and consultation. Is satisfied with current health care professional although still experiences problems in contacts because of autonomy of the patient. |
| 3. Wife of a husband with a psychiatric disorder, diagnosis unclear | Variable, both positive and negative experiences. Has to be proactive in contacts herself. |
| 4. Mother of a son with manic depressive illness | Mostly positive, although she experiences some problems expressing her concern about son's current condition. |
| 5. Brother of a sister who had a severe psychiatric disorder and had been institutionalised for over forty years | Mostly negative, lack of information sharing and consultation. Had to be proactive himself to get information. |
| 6. Mother of a son with schizophrenia | Variable, both positive and negative experiences. |
| 7. Father of a son with schizophrenia and autism | Variable, both positive and negative experiences. |
| 8. Mother of a son with schizophrenia and autism | Variable, both positive and negative experiences. |
| 9. Mother of a daughter who suffers from psychoses and has an eating disorder | Variable, little contact with professionals, lack of information and consultation. |
| 10. Mother of a son with schizophrenia | Very bad experiences in the past, lack of information and consultation. Has now established a good relationship. |
| 11. Mother of a daughter with an undiagnosed psychiatric disorder | Mostly negative, lack of information and consultation. |
| 12. Wife of a husband with schizoaffective disorder | Mostly negative, lack of information and consultation. |
| 13. Daughter of a mother with schizophrenia | Variable, both positive and negative experiences in the past. There is now a good relationship. |
| 14. Sister of a brother with schizophrenia | Variable, both positive and negative experiences. Has to be proactive in contacts herself. |
| 15. Mother of a son with schizophrenia | Variable, both positive and negative experiences. Has to be proactive in contacts herself. |
| 16. Mother of a son with schizophrenia | Variable, both positive and negative experiences. |
| 17. Sister of a brother with schizophrenia | Is not primary carer for her brother and therefore has little contact with health care professionals. |
| 18. Mother of a son with schizophrenia | Variable, both positive and negative experiences. |

cope. So what kind of interaction with professionals do relatives need to enable them to play their active role?

Information

One of the things our respondents highlighted is that they need information about their loved one's mental health status, the professional care he/she receives as well as general information about the condition the patient is suffering from and the functioning of the mental health care system. All respondents mentioned a lack of information (n=18). One respondent explains what information family members need but often do not get. According to her health care professionals should make an appointment to:

(...) provide general information and to agree on certain things. What is someone's role going to be (...), how are the tasks going to be divided [between mental health workers and family members]. (Mother of a son with schizophrenia)

For a long time the husband of a patient did not know what was wrong with his wife and consequently was unaware that her 'weird' behaviour was a result of her illness. At the first ward where she stayed, he was not given any information:

Never had a conversation, never saw a leaflet. Then she went to a different ward. After about three months we got a leaflet: this is what you can expect given your wife's diagnosis. (Husband whose wife suffered manic depression)

Not being informed about the diagnosis was not reported by other respondents. They did report on not getting other information they needed such as information concerning the current condition of the patient, what the treatment would entail, what the role of the family should be, or whether the patient was expected to come home for the weekends. Family members did not receive such information as a matter of course:

A good relationship with family members of the patient is not a given. The relationship is not bad exactly, but you have to keep asking for information yourself. (...) there is no structure in the hospital that keeps you posted. (Brother of a sister who had been institutionalised for forty years)

Other respondents recognised that it was not routine practice to inform them about the patient, although many of them happened to meet professionals that did provide them with (some of the) information they needed (n=15). Apparently it depended

on the individual professional whether family members received information about the patient or not. The social workers we interviewed have dealt differently with the subject of informing family members over the years. In the past they did not inform the patients' family because of the privacy of the patient. Now they feel they should inform family members:

In the past I told [a relative] of a patient: I'm sorry. When you ask how [the patient] is doing I cannot answer (...). These days I changed my opinion on that subject somewhat. (...) I say to the patient: I am going to give information in general terms to let your sister know you're alive and you're not in trouble, otherwise your sister is worried and I don't want that. (social worker)

So the subject of informing family members is dealt with differently in practice by health care professionals. However it is clear that it often raises problems, since many family members feel they do not receive the information they need.

Consultation

Consultation between family members and professionals about the care of the patient is also difficult. Consultation between professional and informal carers can be important to gear their activities to one another. It is also important when the patient is incapable of representing his/her own interests. In that case relatives can advocate for the patient. However, family members often feel that they are not consulted enough (n=18).

I have experienced when I wanted to visit my sister on ward A, that she had been moved to ward B. There was no consultation, it just happened. It also happened that she was lost for a while and then you hear the following day that your sister was lost. (Brother of a sister who had been institutionalised for forty years)

During our observations we saw another family member who had not been consulted about a transferral of her brother to another bungalow in advance but had only been informed about it afterwards. She made an appointment to complain about this:

During the break the sister of one of the patients came by. She called because she was very angry about what had happened. It was clear that she was still unhappy with the situation.

(...) The cleaning woman later told the observer that this woman was right. 'What if your father is in a nursing home and suddenly he is moved, then you'd want to know!'; she said indignantly. (Observations 15-12-2006)

A husband described how he had not been consulted about the decision to discharge his wife although discharge meant that he would have to take care of her again:

They just told me: your wife is coming home earlier. That's the only information I got. (. . .) and we were not ready for that, as a family, and my wife was nowhere near ready. But you had to comply, whether you wanted to or not. (Husband of wife with manic depression)

In order to be heard and consulted family members felt that they had to take the initiative themselves. One had to be assertive, to proactively and repeatedly contact health care professionals, in order to be acknowledged and to be able to represent the interests of the patient:

You just have to be assertive, you should not let them walk all over you, and then you accomplish much more. (Mother of a son with schizophrenia)

Again there are differences between mental health care professionals. Several family members also report positive encounters (n=13). However, in general, consultation between family members and mental health care workers seems to be a problem.

Information for professionals

Contacts between health care professionals and family members are not only important because family members can represent the interests of the patient or provide care for the patient. It is also important because family members know a great deal about the patient.

Information about the patient that family members felt was important for the care provided by professionals was not always taken on board (n=18). However, there were examples where family-professional communication was satisfactory according to family members, which meant that the importance of the information that family members have about the patient was recognised (n=13). One of our respondents related a positive experience whereby the nurse had followed up on a lack of contact since the information she could provide was helpful to the nurse:

I call his nurse regularly because I feel that it's important that she knows what he's like. And when I don't call for some time she calls me and says: 'I haven't heard from you for a while and I really like to hear from you because you know so much about him'. (Mother of a son with schizophrenia and autism)

However, some respondents also had different and less positive experiences. One mother told us how she had been excluded from her son's care, and the far-reaching consequences that had:

They said that it [involving me] would not be good for his treatment. The consequence was that they started working with too little information, which resulted in a faulty diagnosis. Then he attempted suicide for a second time and a third. (Mother of a son with schizophrenia)

A father thought that it was important for him and his wife to talk with the professionals alone about their son, but this was not easy:

It is in his best interest that we do not mince our words for once. And when he's in the room you can't do that. And then I believe privacy is sometimes misused. (Father of a son with schizophrenia and autism)

Other respondents reported on experiences that could be placed between these two extremes. They were listened to but they had to work very hard to be heard.

Many family members (n=12) report that mental health care workers point out that the privacy and the autonomy of the patient prohibits contacts with family members. However, they often feel that the privacy legislation is misused in order to avoid contacts with family members.¹⁵ During our observations we saw mental health care workers making important decisions for patients without informing their family. This also happened when patients were clearly mentally incompetent due to their illness. Although mental health care workers make these decisions with the patient's best interest at heart, it is obvious that the autonomous patient making informed decisions is not always the patient that mental health care workers deal

¹⁵ In the Netherlands the Psychiatric Hospitals (Compulsory Admissions) Act (*Wet BOPZ*) regulates decisions concerning compulsory care. In this act it is stated that patients can only be admitted or treated against their will when they are considered a threat to themselves or others. In other situations mental health care patients can legally make decisions concerning their treatment themselves. The Guardianship Act (*Wet Mentorschap*) makes it possible to appoint a legal guardian for mental health care patients who can take decisions concerning the patients' care, when a judge has decided that the patient is mentally incompetent. This does not happen often in mental health care, however (www.vilans.nl), in practice there are therefore cases, as are described in this chapter, where patients have difficulty making their own decisions and representing their own interests without there being a legal guardian to make decisions on their behalf. In those cases health care professionals and family members may not see eye to eye on who should represent the patient's interests.

with in practice. This makes the argument that family members cannot be informed, consulted or listened to because of the patients' autonomy a questionable one. It raises the question who should represent the interests of the patient and what the role of involved family members should be.

Support for family members

Information exchange and consultation about the patient is important for family members to enable them to play their carer role. However, aside from this family members need support directed at them to be able to cope with their carer role. This could prevent that family members get physical or mental problems themselves due to the burden of caring for their sick relative. Some respondents did not receive any support at all (n=6). Others did, but sometimes in a way that they did not find very helpful (n=3). Two spouses reported that when they finally got some attention they were given the advice to get a divorce.

Supporting family members does not necessarily have to involve difficult or time-consuming procedures. First and foremost family members seek acknowledgement and some understanding (n=8):

When I visit my sister and she doesn't want to see me, then I like a nurse who is there for me and says: 'Hey, yesterday she was doing a lot better', or whatever. (...) I want someone in the hospital who calls me every six months, if necessary: 'How are you doing?' That's 5 or 10 minutes' work. (Brother of a sister who had been institutionalised for forty years)

Other family members need more support. For example, several of our respondents had followed a psycho-education course (n=4). Others had help from a psychologist. Although such help was available, family members had to pursue it actively themselves.

Discussion and conclusion

Discussion

One of the limitations of this study is that we conducted interviews with a limited number of family members (n=18), most of whom were contacted through Ypsilon, a family organisation. It is possible that people that are in contact with or join such an organisation are more critical than other family members. However, the different presentations of our research showed that the problems described in this chapter are indeed widespread in mental health care. Furthermore, although this study was performed in the Netherlands, there are signs that the problems outlined in this

chapter are not typical only for the Dutch situation. The relationship between mental health care professionals and family members is problematic in other countries as well (Peternelj-Taylor and Hartley 1993; Gasque-Carter and Curlee 1999; Ostman, Hansson et al. 2000; Winn, Perkins et al. 2004; Cheng and Chan 2005; Gutierrez-Maldonado, Casqueo-Urizar et al. 2005; Sin, Moone et al. 2005; Legatt 2007; Mordoch and Hall 2008). This means that family members do not receive the institutional support they need to fulfil their carer role.

Although it is often pointed out that the autonomy of the patient prohibits mental health care workers to inform family members, privacy regulation does not have to stand in the way of keeping family members posted (Van de Bovenkamp and Trapenburg 2009). Of course there can be legitimate reasons for a difficult relationship between individual mental health care professionals and the patients' family. It is possible that family members contribute to or even partially cause the development of mental illness (Boevink 2006; Van Os, Krabbendam et al. 2005). It is also possible that patients explicitly ask their physician not to inform their family. However, these possibilities do not explain the difficult relationship between health care providers and family members in general.

Caring for a mentally ill person will remain difficult to some degree regardless of the course of action health professionals take. However, the problems relatives experience do not solely have to do with the severity of the patient's illness (Karp 2001). They are also partly caused by the way society and especially health care professionals relate to relatives. The concept of framing rules introduced by Hochschild can be enlightening to analyse the difficult relationship. Framing rules are rules according to which we ascribe meaning to situations (Hochschild 2003). Karp argues that the strong emphasis in the U.S. on individualism causes problems for family members who care for a mentally ill person. Caring for the patient is framed solely as the family's responsibility, which leads to problems of overload (Karp 2001). In the Netherlands, as in other countries, the problem seems to be slightly different. Health care professionals frame their own role towards patients and family members differently than family members tend to do. Health care professionals in mental health care frame their own responsibilities and tasks solely towards the (autonomous) patient. Patients' family members do not have a part in that relationship. Family members feel that they are closely related to the patient, that it is their responsibility to care for the patient. Family members frame themselves as fellow carers to professionals and feel that they should be included in the professional care process. Family members may be quite right in this. In modern health care one of the dominant paradigms is patient-centred care (Bensing 2000). However, the patient does not stand alone; his social context is also important (Mol 2006). In mental health care the focus on the patient seems especially strong, due to the anti-psychiatry movement in the

1960s and 1970s (Crossley 1998; Thomes 2006). Since that period it is felt that mental health care patients need to be empowered (Thomes 2006). Patient autonomy has become an important concept to ensure this empowerment. Mental health care professionals referring to the autonomy of the patient to explain why they cannot share information with family members show that these ideas have become ingrained in the culture of mental health care. Yet by referring to their role as informal carers, family members feel that they are entitled to information and support from health care professionals, which they need to fulfil this role. Thus, different framing rules lead to tensions between the family rights' perspective family members adhere to and the patients' rights perspective that has become dominant among professionals in mental health care (Karp 2001; Davis 2002).

Conclusion

On the basis of our study we conclude that the relationship between health care professionals and family members of mental health patients is problematic. All of our respondents have had negative experiences in the contacts with mental health care workers. Although many of them also reported on positive contacts, the general picture is gloomy. Family members find that this difficult relationship causes problems with regard to information exchange, consultation and support. This troubled relationship is a problem when family members are expected to fulfil their carer role. When they are not well enough equipped with information and support this becomes difficult. Although patient-centeredness is a very important concept in health care (Grit, Van de Bovenkamp et al. 2008; Bensing 2000; Lewin, Skea et al. 2001), when focused on too much and in consideration of other factors it can lead to undesirable results, such as neglecting the social network around the patient in the case of mental health care.

Practical implications

This study shows that it is important to improve the contacts between mental health care workers and family members of patients who take care of the patient often for as long as they live. Practitioners should provide information to family members, they should treat them at least partly as fellow carers, consult with them when necessary and support family members to enable them to play their carer role. The fact that health care professionals already deal with the subject of autonomy and patient laws differently (Pols 2004), shows that changes are possible. Some training for professionals may be necessary to reframe their perception of the role of family members.

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CHAPTER SIX

A COMPARATIVE REVIEW OF FAMILY-PROFESSIONAL CONTACTS: WHAT MENTAL HEALTH CARE CAN LEARN FROM ONCOLOGY AND NURSING HOME CARE

This chapter was submitted for review as

Van de Bovenkamp H.M., M.J. Trappenburg, A comparative review of family-professional contacts: What mental health care can learn from oncology and nursing home care

Introduction

Illness does not only affect patients. It also affects their family members. Many family members take on carer roles and have to cope emotionally with the patient's condition and their caring obligations (Bittman, Fast et al. 2004; Burden, Cooper et al. 2000; Timmermans, Schellingerhout et al. 2004). Moreover, policy-makers increasingly expect family members to care for their sick or disabled relatives (*ibid.*). This fits the policy trend of active citizenship.

Modern citizens are expected to take care of themselves and each other before turning to the state for professional help. In addition, according to many Western governments, citizens have to play an active role in the services they use (Tonkens 2006; Clarke, Newman et al. 2007; Trappenburg 2009). The policy directed at attributing an active role to patients, a prominent item on the policy agenda in many Western countries (Clarke, Newman et al. 2007; Grit, Van de Bovenkamp et al. 2008), is part of this trend. The same goes for the policy of giving an active role to family members of patients. Because of the increased emphasis on the carer role of family members it becomes ever more important that health care professionals recognise their position and their needs. Contacts between health care professionals and family members are important to equip and support family members to play their role and to coordinate professional and non-professional help in order to provide good care for the patient.

In general the position of family members seems to be acknowledged by health care professionals. However, mental health care is different in this regard. Family members of psychiatric patients report numerous difficulties. They find it hard to share information with mental health care professionals because professionals are not willing to listen or provide them with information. According to family members mental health professionals do not consult them enough. Some family members indicate that they need more support to be able to cope with their relative's situation as well as their own grief. Family members report that mental health care workers refer to the privacy and autonomy of the patient which would prohibit them from contacting family members. These were the findings in our own empirical research (Van de Bovenkamp and Trappenburg 2009) but our findings are part of a general pattern. Many other studies emphasise the importance of family members in the care process and their need for support (Cheng and Chan 2005; Gasque-Carter and Curlee 1999; Gutierrez-Maldonado, Casqueo-Urizar et al. 2005; Harden 2005; Laidlaw, Falloon et al. 1999; Legatt 2007; Magliano, Fiorillo et al. 2005; Rose 1997; Struening, Perlick et al. 2001; Zipple 1990) while reporting simultaneously that in practice mental health care professionals continue to pay little attention to family members (Gasque-Carter and Curlee 1999; Harden 2005; Legatt 2007; Magliano, Fiorillo et al. 2005; Rose 1997; Zipple 1990; Clarke 2006; DiRienzo-Callahan 1998; Magliano,

McDaid et al. 2007; Marsh 1999; Ostman, Hansson et al. 2000; Sin, Moone et al. 2005; Winefield and Burnett 1996; Winn, Perkins et al 2004).

The results of our study made us wonder whether the situation we found is something that is indeed specific to mental health care or whether this is a more widespread problem. Our previous study also suggests that tensions can arise between the policy directed at activating and empowering patients (by emphasising their autonomy) and the policy directed at activating their family members. These tensions may lead to family members being shut out of the professional care process while simultaneously being expected to provide informal care. In this chapter we will explore this subject further. We will answer the following research question: *how do health care professionals relate to family members of patients in different health care sectors and how can possible differences be explained?* Our research consists of a systematic literature review with the aim to make an inventory of this subject. We chose the sectors oncology, nursing homes and mental health care for our comparison. All three sectors relate to patients with severe conditions. Furthermore, the effects on the patient's network, both in terms of caring for the patient and in coping with the situation themselves, are substantial. Because of this, in all three cases contacts between family members and professional health care workers are important.

Following the Methods section we first describe the articles we found, after which we will describe professional – family member contacts in oncology, nursing homes and mental health care. We will then focus on similarities and differences between sectors. In the Discussion section we will explore some explanations for the differences we found, reflect on some limitations of this study and offer our conclusions and some ideas on how to improve the situation.

Methods

To explore the contacts between health care professionals and family members in different health care sectors we performed a literature search in the Pubmed/Medline database, the Cochrane Library and the Web of Science in the period 1998 - June 2009. We restricted our search to this timeframe for the practical reason of availability of the articles which decreased substantially with time. Also we were especially interested in the current situation regarding this subject; our goal was not to provide a historical overview. Key words used were: family member professional communication mental health (220 hits), family member professional communication nursing homes (69 hits) and family member professional communication oncology (93 hits). These key words were chosen because contacts between the two parties in the different sectors are captured this way. Furthermore, communication captures different contacts between family members and professionals, for instance sharing information and consultation.

We excluded articles that did not focus on family-professional contacts or focused on other sectors of care. In addition we excluded articles that focused on the care of young children since in these cases the parents are the formal representatives of their children which make them the primary focus of communication for health care professionals.¹⁶ Furthermore, we excluded articles on end of life decisions, since these represent a very specific case and cannot easily be compared to other family-professional contacts. To conclude we excluded articles that were not written in English and which were not available to us.

After this preliminary analysis of the articles we included 20 studies on oncology, 21 studies on the situation in nursing homes and 26 studies on mental health care. Included studies consisted of empirical studies, descriptive studies¹⁷, reviews and opinion articles.

We performed a content analysis on the included articles. The subjects for this analysis followed from our research question and a preliminary analysis of the data. We analysed the articles on the following subjects: (1) the nature of the study (empirical or not), (2) the focus of the article (were family member contacts the primary focus of the article) (3) the role of family members in the care process (4) contacts between family members and health care professionals, (5) difficulties encountered and (6) recommendations for the future. To increase the validity of the process, the first author presented the material to the second author so as to improve intersubjectivity.

Results

We will first describe the articles that were included in our study. Secondly, we will go into the nature of the contacts between family members and health care professionals in the different sectors. After that we will concentrate on the differences we found.

Description of the articles

Our search on family members in oncology resulted in few articles that specifically focused on the role of family members; mostly family members were one of the subjects discussed in the articles. Of the twenty included articles only four specifically focused on professional- family member contacts [3, 7, 9, 14]. The articles by Turner et al. described and studied how nurses should relate to children of cancer patients. Ozdogan et al. performed a survey amongst relatives on their attitudes towards in-

¹⁶ We included articles which concerned the care for minors who had their parents as their legal representatives but who were old enough to form their own opinion about their care.

¹⁷ For instance a description of an intervention that was developed.

forming patients of their cancer diagnosis in Turkey. Spetz et al. described how a specialist nurse can support family members of cancer patients. The other included articles did not have family members as their core focus; the subject was mentioned in passing. Firstly, there were five articles, based on interviews and surveys, on the communication and information preferences of patients which included their preferences regarding the role of their family [2, 4, 8, 19, 20]. Secondly, there were three articles that empirically studied health care and communication preferences of both patients and their carers [6, 12, 16]. Thirdly, three articles described health care practices. In these articles there was also attention for, but not a special focus on, family members [1, 10, 18]. Family members were also mentioned in review articles on truth telling in Italy and on giving bad news [11, 15]. To conclude an article described how to deal with differences of opinion between patients, family and professionals [13], one article described the subject of cancer related fatigue (and the communication concerning this subject) [17] and an opinion article was included on how family members, patients and the health care team negotiate their way through the illness trajectory by means of communication [5].

Family members were the specific focus of a large part of the articles on nursing homes, namely eighteen of the twenty-one included articles. Of these articles there were two that studied, on the basis of a survey and interviews respectively, the perspective of family members on the quality of care [22, 32]. One article presented the findings of a survey on the perspectives of family and staff on the needs of patients [37]. Five articles empirically studied or described interventions to improve the role of family members or the relationship between staff and family members in the care process [23, 28, 29, 33, 41]. Three articles studied nurses' perceptions of their relationship with family members by means of interviews and a survey [27, 34, 36]. Two articles reported the findings of interviews with family members on their views on the relationship with nursing home staff [38, 40] and three articles reported on focus group and interview studies on the perception of this relationship of both family members and nurses [26, 31, 39]. In addition there was an article, based on interviews and observations, on how family members try to adjust to their changed relationship with their relative when their relative is admitted to a nursing home [24] and an article that described models of family behaviour and of physician involvement in family counselling [25]. Aside from these articles with a specific focus on family members there was an article, based on focus groups and interviews, on challenges experienced by professionals, amongst them were contacts with family members [21], an article describing how professionals can improve communication including communication with family members [30] and an article on medical decision-making processes including the role of family members therein, based on questionnaires [35].

Family members were also the specific focus of most of the included articles on mental health care (twenty-two of the twenty-six). Three, two of them descriptive and one on the basis of interviews, were on interventions to improve the role of and communication with family members [42, 43, 52]. Eight articles empirically studied the experiences and needs of family members in their relationship with professionals [45, 46, 48, 49, 54, 56, 59, 65]. There was also a descriptive study on this subject [51]. Three articles, based on surveys and focus groups respectively, were on the experiences of professionals with family members and their views on family members [57, 62, 64], and two articles empirically studied the views of both family members and professionals [58, 61]. Two articles, one descriptive and one empirical, studied barriers to family participation in mental health care [50, 60]. To conclude there was an article on contacts between clinicians and family members based on a client survey [55], an opinion article on differences concerning the role of family in Western and South Asian cultures [63] and a review article on the role that has been attributed to family members as a causal factor in developing a mental illness [66]. The four remaining articles did not specifically focus on family members, although relatives were mentioned in passing. One article, based on a survey amongst physicians, focused on family physicians' deliberations regarding shared decision-making with adolescent patients [47]. The remaining articles were a review article on the effects of patient and family involvement on professional autonomy [53], a survey study on the development of a guideline on how members of the public (including family members) should help someone experiencing psychosis [44], and a descriptive article on mental health advance directives (in which the desired role of family members can be described) [67].

We might conclude from the description of the studies that in oncology the role of family members is hardly subject of discussion. In nursing homes and mental health care the relationship between professionals and family members is a subject of study in its own right. This may be an indication that in the latter two sectors contacts between family members and professionals are a more frequent phenomenon or that they raise more discussion or problems than in oncology. We will now proceed with a description of the role of family members in the different sectors of care to explore whether this difference of focus comes from a different attitude towards family members in the sectors studied. An overview of the articles can be found in the tables including further information about the nature of the studies.

Oncology

Family members of oncology patients take on many caring activities [6, 9]. Patients value the support of their family members and want them to be present at consultations [2, 8, 10, 16, 19]. Contacts between family members and health care profes-

sionals in oncology are considered part of the job of professionals. In the studies patients and family members are often mentioned together [1, 6, 10, 12, 15, 17, 18]. It is generally recognised that cancer does not only affect the patient but also his relatives. They both need to be informed and both need support from professionals to deal with the situation [2, 5-9, 12].

Some difficulties are reported though. In some cases the focus on the family seems to be too strong. Young et al. (2003) report that in case of young patients, the strong role of parents can marginalise patients themselves and result in patients not getting the information that they would like to have [16]. In family focused countries such as Italy and Asian countries, the strong focus on the family also raises questions for some authors. In these countries it still happens that health care professionals inform family members of the diagnosis and leave it up to them to inform the patient or not. This can result in the patient not being informed because his family members think this is best [2, 8, 11, 13, 14]. However, in most countries the situation in oncology is that communication and support activities of professionals are directed at both patients and family members. Of course daily practice is not always perfect. Professionals sometimes have a hard time working with difficult family members [5] and young children of severely ill patients [7]. In two studies family members and patients report that they do not get all the information and support that they feel they need [6, 12].

An overview of the articles on oncology can be found in Table 1.

Nursing homes

The relationship between family members and professional health workers is somewhat different in nursing homes. An important reason is that patients or residents are often in such a dire state that they cannot represent their interests themselves. In these cases family members can make decisions for them. Contacts between professionals and family members occur regularly. It is acknowledged that family members can represent the interests of the patient, that they may have important information about the patient which professionals can use to provide good care, that they play an important support role for patients and that they are affected by the condition of their family member themselves [21-24, 26, 27, 30, 32, 32-35, 38-40]. Hence, communication with and support of family members is considered essential [22-26, 30, 32, 34, 38]. Professionals report that family members are important and that contacts with family members are part of their job, although they do not always have the highest priority [27, 34]. Whereas in oncology the patient and his family are often mentioned as one, in nursing home studies authors write about building partnerships between professionals and family members which are deemed important to provide good care to the patient [23-25, 27, 28, 32, 40].

The contacts between family members and professionals in nursing homes may cause problems, however, and many studies conclude that this relationship should be improved [21-24, 26-28, 30, 32, 38, 39, 41]. Family members report that they want more and better contacts with professionals [22-24, 26, 32, 38, 39]. Family members also report on not being listened to or not being taken seriously [26]. Professionals sometimes find it difficult to attend to family members [21, 23, 25, 27, 34, 39] and it is reported that they lack the necessary skills to do this well [21, 25, 39]. In addition it is claimed that the number of professional - family contacts is insufficient due to time constraints and the structure or philosophy of the care institution [27, 28, 34]. Several studies suggest ways to improve the situation, for example by training professionals and family members, by organising family meetings or by providing checklists [21, 23, 25, 28, 33, 36, 39, 41].

An overview of the articles on nursing homes can be found in Table 2.

Mental health care

The studies on mental health care show a growing awareness of the fact that family members of mental health patients play an important role in the care of their sick relative. It is acknowledged that family members take on practical care activities, that they represent the patient's interest when the patient cannot (temporarily) do this himself, that they have important information about the patient and can provide support to the patient [43, 46, 49, 52, 54, 57, 58, 61, 62, 64]. Family members of mental health patients can also be considered fellow carers to professional workers which makes working in partnership important. The effects of a mentally ill patient on the lives of his or her family members can be substantial [49, 52, 54, 56-59, 64]. It is therefore concluded that communication between family members and professionals is important, as is professionals providing family members with some support to deal with the situation [43, 46, 47, 50, 54, 57, 59, 61, 62, 64]. However, contacts between mental health care professionals and family members seem to be problematic. This is the case not only for practical reasons similar to the ones in other sectors, such as lack of skills and resources [46, 57, 60, 62] but for more principled reasons as well.

It is reported that some mental health care workers still adhere to the idea that family members, especially mothers, are a cause of the condition of the patient [42, 56, 62, 64, 66], which was a common notion from the 1950s till the 1980s [66]. Although at present much more is known about the causes of mental illness, this belief still frustrates contacts between the two parties. More importantly contacts between family members and professionals are considered problematic by mental health care workers because of issues of confidentiality and privacy of the patient [42, 43, 46, 47, 49, 50, 54, 56, 57, 59-61, 63, 65]. It is felt that mental health workers cannot con-

sult with or inform family members because this would damage professional-patient confidentiality. As a consequence family members complain that they lack information about the diagnosis, about the care plan and even general information about mental health care. Family members also feel that they are not consulted enough, not even when the patient is discharged and his or her family is supposed to step in and take on caring activities. Lastly family members lack support from health professionals [45, 48, 54, 55, 57, 59, 60, 65]. Although many professionals in mental health care consider the contacts with family to be problematic, not all of them do. Variation in contacts with family members is reported; some professionals do inform, consult with and support family members [42, 46, 49, 61, 65]. Studies reporting on problems between family members and mental health care professionals all argue that contacts between family members and professional staff need to be improved. Training professionals, increased attention in their education and advance directives could contribute to improving the situation [42, 43, 50, 54, 62, 64, 65, 67].

An overview of the articles on mental health care can be found in Table 3.

Comparison of the different sectors

When we compare the situation in the three sectors several differences can be identified. First of all the position of relatives is framed differently. Whereas in oncology family members and patients are mentioned together and communication is directed at both, in nursing homes relatives are considered possible partners of professionals, the both of them can provide care for the patient together. This latter idea can also be found in the literature on mental health care.

Also, the number and nature of the problems in the relationship between family members and health care workers differ between the sectors. The reason why we found few articles focusing specifically on family members in oncology seems to be that health care professionals focus both on the patient and his family and that this is the normal way of doing things. Still, even in oncology communication between health care workers and patients and their relatives can be improved. Apart from some cultures, in which the focus on relatives is too strong and goes to the detriment of patients themselves, our review does not show any structural problems in the relationship between oncology staff and relatives of patients however.

Although more problems are described in the relationship between family members and nursing home staff, these problems are mostly of a practical nature, like in oncology. Family members of patients or residents in nursing homes are often involved in their relatives' care. An important difference is that residents cannot always voice their preferences or represent their interests themselves. In such a case family members also act as interest representatives. In addition they are considered fellow carers of health care professionals. During visits to their relatives family members

like to contact professional staff. This is unlike oncology, where relatives can simply schedule to accompany patients to an oncology consult. In nursing home care contacts between family members and nursing staff are less structured and partly depend on chance. This could also be part of the reason why more problems arise in this sector. However, contacts with family members are generally considered to be part of the job of nursing home staff.

Most problems occur in the contacts between relatives of psychiatric patients and health care professionals. What is interesting in this sector is that these problems seem to go beyond ordinary communication problems and do not seem to be caused by time constraints alone. In mental health care health care workers consider contacts with family members to be problematic in principle because of autonomy and confidentiality issues. This difference with other health care sectors is also sporadically reported in the studies [48, 62]. In contrast to health care contacts with family members in oncology and nursing homes, contacts for the purpose of information exchange as well as to provide support, are not considered part of the job of mental health professionals. Although family members in mental health are arguably equally important in the care and support for the patient, contacts with family are not part of the daily routine for mental health care workers. It is felt that the autonomy of the patient makes these contacts problematic.

Although the differences are partly due to the condition patients are suffering from, which determines for instance why family members in nursing homes act as patient representatives, the results show that this is not sufficient explanation for the differences we found. In the remainder of the chapter we will explore other reasons which can explain this peculiar situation in mental health care.

Discussion: looking for explanations

Our review study shows that the relationship between family members and health care professionals can be a source of problems in varying degrees. In mental health care the position of family members in the care process is much debated and considered problematic. The patient's autonomy and patient-professional confidentiality are often referred to. This is the most interesting finding of the study. Whereas in oncology and nursing home care the implicit assumption is that sharing information and consulting with family members is a good thing, the situation in mental health care is the other way around: it is implicitly assumed that family members should not be informed or consulted with. This situation is undesirable since caring for a relative with a mental illness has a large impact on family members. Moreover, they need to be equipped for their carer role, in order to provide good quality care to the patient (Van de Bovenkamp and Trappenburg 2008). Compared to other types of informal care, the caring role of family members is even more demanding in mental health care

because of the unpredictability of psychiatric illnesses, recurring crises and the refusal of patients to acknowledge that they are ill (*ibid.*). Moreover, family members experience a lack of understanding from people around them and from society in general (Magliano, Fiorillo et al. 2005; Rose 1997). The effects of caring for someone with a severe mental illness are substantial. Both the objective and the subjective burden are high (Gasque-Carter and Curlee 1999; Gutierrez-Maldonado, Casqueo-Urizar et al 2005; Laidlaw, Falloon et al. 1999; Legatt 2007; Magliano, Fiorillo et al. 2005; Rose 1997; Stuening, Perlick et al. 2001; Marsh 1999; Ostman, Hansson et al. 2000; Sin, Moone et al. 2005; Marshall and Solomon 2004; Peternej-Taylor and Harley 1993).

In this part of the chapter we will explore reasons that can explain the difficulties in the relationship between professionals in mental health care and family members. We found that in mental health care the autonomy of patients and their right to confidentiality is used as an argument by health care professionals as to why they cannot inform family members. However, patient autonomy and confidentiality are generally cherished values in health care. The importance of patient confidentiality in health care dates back to the beginning of medicine. In medical ethics as well as in legislation it is established that information about the patient should not be shared with a third party without the patient's permission. The autonomy principle puts this decision in the hands of patients themselves (Hatlev 2007; Sokalska 2004). The autonomy of the patient receives even more emphasis in the policy directed at activating and empowering patients, which features prominently on the policy agenda in many Western countries (Clarke, Newman et al. 2007; Grit, Van de Bovenkamp et al. 2008). However, on the basis of our study we conclude that in oncology wards and nursing homes confidentiality and autonomy do not figure in the relationship between professionals and family members. Sharing information with family members seems to happen on the basis of implied consent, a mechanism that can also be witnessed in the communication between health care professionals (Hatlev 2007; Sokalska 2004). Confidentiality and autonomy are implemented differently in mental health care. Apparently legal rules regarding health care are not applied in the same manner across different sectors. The theory on the social working of legal rules might provide us with a (partial) explanation for this phenomenon (Griffiths 1996, 2003).

Professionals in mental health care are confronted with additional legal rules concerning compulsory admission of patients (Legemaate 1995). This additional legislation makes contacts between mental health care professionals and judges and other representatives of the judicial system more common than in other sectors of care. Griffiths uses the concept of SASFs (semi-autonomous social fields) to explain the importance of the use of rules within a social context. People in a certain social context do to a great extent decide which rules are important in that environment. How legal rules work out in practice depends largely on these decisions. Rules are therefore so-

cially constructed to suit a social context. According to Griffiths the medical sector enjoys a high level of autonomy regarding the application of legal rules. The social context is one of self-regulation. Medical professionals can decide whether or not to uphold legal norms, and in mental health care professionals seem to display a high regard for the law in their day to day work. They interpret the law conservatively as the study of Marshall & Solomon (2003) included in our review shows. The fact that these professionals are confronted much more often with the judicial system in their professional practice than other medical professionals could cause them to adhere strictly to the legal rules. Griffiths argues that the fact that people are aware of instances in which a rule was enforced, can have important effects on their behaviour. This type of experience might pave the way for other formal judicial rules and regulations that could influence the behaviour of mental health care professionals in other decisions. For example, the decision to inform the patient's family members or not.

Additional legislation is not the only explanation for the preponderance of patient autonomy in mental health care compared to other sectors of care. The anti-psychiatry movement active in the 1960s and 1970s (Crossley 1998; Thomes 2006) also put an emphasis on this notion. This movement brought out the unequal relationship between psychiatrists and patients. The movement strove for more socially oriented, democratic and alternative care. Patients should be empowered and recognised as full-fledged partners in care. Since this period the care of the mentally ill has changed substantially and the position of patients has been strengthened. The concept of patient autonomy was an important tool for patient empowerment. However, the enduring emphasis on patient autonomy seems to have led to a neglect of family members. The focus on patient autonomy results in a focus on the patient as an individual which sets him apart from his family. In other health care sectors the struggle against medical paternalism has never become as fierce as in mental health care, hence the struggle for patient autonomy has never caused a split between the patient and his or her family (Trapenburg 2008). In other sectors of health care, the recognition that patients should be involved and informed went hand in hand with the recognition that family members should also be involved.

Our review shows a third factor in the history of mental health care that could also explain the difficult relationship with family members: the fact that the family was often blamed for the patient's mental illness (Harden 2005; Schmetzer, Lafuze et al. 2008; Kaas, Lee et al. 2003; Riebschleger 2002; Wuerker 2000). Although these theories have now been rejected family members are sometimes still blamed for the condition of their relative (Harden 2005; Schmetzer, Lafuze et al. 2008; O'Connell 2006; Kaas, Lee et al. 2003; Riebschleger 2002). Obviously, if professionals feel that family members are part of the reason why their client is ill in the first place, communication with and support for family members is given low priority or may even be considered a bad thing.

We should note some limitations to this study. First of all, we performed a limited literature review, which limits the generalisability of the findings. Other health care sectors could be included for instance, which would have provided us with a broader overview of family member – professional contacts in health care. Another way to extend the search is by using other databases or key words. It is possible that this would have given us additional insights into this subject. However, we feel that since the results are based on the analysis of a substantive number of articles that provided us with a consistent picture of the situation in the different sectors, the study provided us with a good preliminary overview of family member – professional contacts. Moreover, this study offers insight into important differences between the three health care sectors and possible perverse effects of focusing too strongly on patient autonomy.

To conclude, family member - professional contacts are important, especially considering the fact that policy-makers increasingly expect family members to provide informal care (Burden, Cooper et al. 2000; Timmermans 2003). It is therefore important to acknowledge family members as stakeholders in health care. The situation in mental health care may be improved by applying the working method of professionals in other sectors of care. Informing, consulting and supporting family members when necessary should also become routine practice for mental health care workers. The fact that family members take on many caring responsibilities justifies their involvement in professional care (Touwen 2008). When family members are seen as fellow carers, implied or presumed consent could also be applied to them, when it is necessary to communicate or inform each other in order to provide the patient with the best care (Hatlev 2007).¹⁸ Furthermore, it is important to note that for certain mental health care patients to become an equal, informed partner to the physician is an unattainable ideal. Consequently, just like residents in nursing homes these patients need someone to represent their interests when they are unable to do so themselves. A family member, who is in close contact with the patient, could perform this role. At the same time the tension between active patientship and the active role of family members needs to be recognised and should receive attention of researchers and policy-makers. When the individuality and autonomy of the patient is emphasised too strongly it can have undesirable effects on family members. Since patient empowerment is a high priority of policy-makers in many Western countries it is important to recognise this effect.

¹⁸ Naturally, a situation could arise in which it is deemed better for an individual patient to decrease the contact with his or her family members, but then this should be explained to the patient's family members. In addition, non-personal information about a mental condition or the mental health care sector in general should be provided in all cases.

Table 1 Oncology

| Article | Type of study | Focus article | Findings |
|--------------------------|---|---|--|
| Weingart et al. 2009 [1] | Descriptive US | Examination of patient oriented teamwork training for oncology patients and their families. The article does not have family members as its special focus, they are mentioned in passing. | Patients and family members are mentioned together. The training program gives them more control. |
| Repetto et al. 2009 [2] | Empirical, structured interviews with oncology patients over 65 (622). Italy | Research into the communication preferences of elder patients. The role of family members was one of the items in the study. | The majority of patients consider their family as their main source of support and want them to be informed and participate in consultations. They also need to be supported by health care professionals. Sometimes family members are informed but the patients themselves are not, this is considered an undesirable situation. |
| Turner et al. 2008 [3] | Descriptive Australia | Description of the development of a manual to guide supportive care. It described the effects on children of patients and how to deal with them. | A cancer diagnosis affects the whole family including the children of the patient. It is considered part of the job of nurses to support patients and their children, although they do find this difficult and do not know how to do this, they therefore need to be trained. |
| Piredda et al. 2008 [4] | Empirical, survey amongst oncology patients (111). Italy | Research on patient communication preferences. Family members are one of the items in the study. | Most patients want to be informed together with their family. They do not want their family to be informed before them which is in contrast with the idea frequently held by Italian physicians and families. |

Table 1 Oncology (continued)

| Article | Type of study | Focus article | Findings |
|--------------------------|---|--|--|
| Baider 2008 [5] | Short communication article. | Examination of how communication, in its multi-faceted forms, can be the conduit by which the patient, family and health care team negotiate their way through the illness trajectory. | Having a sick relative is not easy for family members. Professionals sometimes have a hard time dealing with family members since family members can be difficult. |
| Coon et al. 2007 [6] | Empirical, diary of a wife of a cancer patient. New Zealand | Examination of what is important in health care from the perspective of patient and carer. | Patient and family members are mentioned together. Family members are severely affected by a cancer diagnosis. Family members are often primary carers. Communication and support of patients and family members is very important but does not always happen satisfactory in practice. |
| Turner et al. 2007 [7] | Empirical, 4 focus groups with nurses (24) and interviews with nurses (5). Australia | Study on the perceptions of nurses about the support of children with a parent with cancer. | Having a parent with cancer has a large impact on children, parents find it difficult to deal with this and need support from nurses. Nurses perceive this as their job but do find it difficult; they identify a lack of knowledge and skills. They also identify a culture in which the needs of family members are peripheral to clinical care. |
| Fujimori et al. 2007 [8] | Empirical, survey amongst cancer patients (529). Japan | Study on patient preferences about the disclosure of bad news. One of the items focuses on the role of the family. | Patients want their family members to be informed and professionals to show concern about the feelings of their family. In Japan the patients' family is often informed before the patient. |

Table 1 Oncology (continued)

| Article | Type of study | Focus article | Findings |
|---------------------------|--|--|---|
| Spetz et al. 2005 [9] | Empirical, field notes with patients and family members. Sweden | Investigation of how the family responds to the implementation of a specialist nurse as a resource for the patient and the family. | Most of the family members in the study have much contact and are happy with the specialist nurse; she provides them with practical and emotional support and information. The patient and his family are mentioned together in this article as well as separately since they can have different needs. However this is not considered a problem. |
| Kataoka et al. 2005 [10] | Descriptive Japan | Description of the concept of multidisciplinary medical treatment used in a cancer centre in Japan which will allow for medical care as desired by patients and family. Not a special focus on family members. | Important to provide the best care to patient and family members. The patient and his family are mentioned together. |
| Surbone et al. 2004 [11] | Literature review Italy | A review of the published data on informed consent and truth telling in Italy. | Family members still act as a filter of information in Italy which could mean that the patient is not informed about his diagnosis. |
| Salminen et al. 2004 [12] | Empirical, survey amongst patients (96) and spouses (72). Finland | Examination of the needs and sources of disease information of breast cancer patients and their spouses. Family members are not the specific focus of the article but it is recognised that they need information as well. | Patients and family members are mentioned together. Family members are also affected by the diagnosis. Patients perceive a lot of support from their family. A number of them regularly accompany the patient to appointments. Some spouses reported that their information needs were ignored. |

Table 1 Oncology (continued)

| Article | Type of study | Focus article | Findings |
|------------------------------|--|---|--|
| Kissane 2004 [13] | Editorial | Examination on how to deal with differences of opinion between patients, family and health care professionals. | The position of family members is different depending on cultural context. Autonomy is not privileged above other principles but is limited by a tension between the unencumbered self and an individual in a contextualised world. |
| Ozdogan et al. 2004 [14] | Empirical, survey amongst family members (150). Turkey | Evaluation of relatives' attitudes towards informing cancer patients about their diagnosis. | Patients are not always informed about their diagnosis because the family thinks this is best (66%), they feel that the news would extremely upset the patient or they think the patient did not want this. On the basis of the literature it is concluded that this situation is undesirable. |
| Fallowfield et al. 2004 [15] | Literature review | Review of research on giving bad news. Family members are not a specific focus of the article but are mentioned in passing. | Patients and family members are mentioned together. It is important to improve communication about bad news. |
| Young et al. 2003 [16] | Empirical, semi-structured interviews with parents (19) and patients (13). UK | Examination of young people's and parents' accounts of communication about cancer in childhood. | Parents take on an executive like role; they often decide what information their children get. The patients welcomed their parents' involvement, however some express unease with the constraining aspects of their parents' role. This did not mean that the young people regarded their parents' involvement in communication as inappropriate in principle. |

Table 1 Oncology (continued)

| Article | Type of study | Focus article | Findings |
|-----------------------------|--|---|--|
| Jakel 2002 [17] | Descriptive | Overview of cancer related fatigue. Family members are not a special focus in the article. | Patients and family members are mentioned together. The importance of informing and communicating with them is emphasised. |
| Radziewicz et al. 2001 [18] | Descriptive | Focus on how to deliver bad news. Family members are not a special focus in the article. | Patients and family members are mentioned together. Nurses should support and inform patients and their family. |
| Sapir et al. 2000 [19] | Empirical, interviews with patients (103). Israel | Evaluation of patients' knowledge of their diagnosis and stage, their expectations of medical and nursing staff, and issues related to communication. Family members are not a special focus in the article. | Most patients report that they discuss news with and consult about treatment options with family members. A small percentage (6%) wants information conveyed to family members but not to themselves. |
| Carlsson et al. 1998 [20] | Empirical, interviews with patients (24). Sweden | Focus on the information patients receive. Family members are not a special focus in the article. | There are several advantages of having a relative present when receiving information. However not all of the patients had a family member present. When it is in accordance with the patient's and family's wishes, efforts should be made to provide information at times when both can participate. The patient and the family should be considered as the unit of care. |

Table 2 Nursing homes

| Article | Type of study | Focus article | Findings |
|--------------------------|--|---|--|
| Chang et al. 2009 [21] | Empirical, focus groups (5) and in depth interviews (20) with health care professionals. Australia | Examination of the challenges for key professional providers of care for people with advanced dementia living in residential aged care facilities. Family members are one of the points that are discussed but not the specific focus of the article. | Family members function as proxy decision makers. Health care professionals sometimes find it difficult to deal with family members, they feel they lack knowledge and skills. |
| Mellor et al. 2008 [22] | Empirical, interviews with family members (15). Australia | Examination of the perspective of family members of depressed elderly care recipients on the skills of professional carers in detecting and monitoring depression. | Family members act as interest representatives of patients. Signs of depression are often overlooked by professionals. Communicating about depression is difficult, whereas this is not the case in communication about the physical condition of the patient. |
| Robison et al. 2007 [23] | Empirical, RCT. US | Evaluation of a training project to improve the relationship between family members and professionals. | The importance of a partnership is emphasised in order to achieve optimal quality care. The intervention increased and improved involvement. Residents' behavioural symptoms also improved as a result. |
| Kellet 2007 [24] | Empirical, interviews with family caregivers (14) and participant observations. Australia | Exploration of the ways family members reconstruct meaning through seizing possibilities for positive care giving in nursing homes. | Family members have to deal with stress and fear. Communication with professionals is therefore important and they need to be supported. This does not always happen satisfactory in practice. A genuine partnership needs to be established. |

Table 2 Nursing homes (continued)

| Article | Type of study | Focus article | Findings |
|----------------------------|---|--|--|
| Bluestein et al. 2007 [25] | Descriptive | Study on how certain theoretical models can inform communication with family members. | Professionals have two patients: the patient himself and his family, the latter also needs support and information. In practice this communication can be a challenge because of difficult family members. In addition professionals feel they lack the necessary skills and have concerns about time demands. A model is developed on how to improve this. |
| Marziali et al. 2006 [26] | Empirical, interviews with family members (9) who had persistent concerns about the care of their relative. Focus groups (2) with nurse managers. Canada | Examination of institutional and family caregiver characteristics that contribute to the failure to resolve families' persistent complaints. | Family members experience stress, some of them need support. The family members in this study report problems in communication, mostly they felt that what they had to say was misunderstood, ignored or challenged. Factors associated with persistent discord are: perceptions of staff as incompetent, interfamilial conflicts and unresolved psychosocial issues. Contributing institutional factors are: staffs vulnerability in the face of challenges to their professional competence and stress due to disproportionate amounts of time spent educating and supporting health care aids to cope with distraught families. |

Table 2 Nursing homes (continued)

| Article | Type of study | Focus article | Findings |
|--------------------------|--|--|--|
| Weman et al. 2006 [27] | Empirical, survey amongst nurses (210). Sweden | Understanding of those factors that influence how nurses are able to work together with family members of older people living in nursing home facilities. | Working together is in the interest of all the parties involved. Nurses feel that communicating with family members is important in their work. They also recognise that it is important to support family members, however they do not always have time for this. |
| Roshier et al. 2005 [28] | Empirical, pre-post study, survey amongst family members (37) prior and after two years of the implementation of an intervention. US | Examination of the effect of an intervention (the Eden Alternative which concerns a holistic model of care), on family satisfaction. | The Eden Alternative provided many opportunities for family involvement. The improved satisfaction scores reflected greater communication and interaction among families, staff and residents. |
| Boise et al. 2004 [29] | Opinion article US | Exploration of the role that family members play in providing person-centred care and ways to successfully achieve family participation in this model of long term care. | Family members are important in person-centred care. They can play both a negative and a positive role. Nurses need to be able to deal with them. |
| Winn et al. 2004 [30] | Clinical practice article US | Provision of practical information for health care professionals on improving communication, including with family members. | Family members and patients are mentioned together. Health care professionals need to guide them through difficult decisions. They need to be informed and able to attend plan conferences. Family members also need to be supported. |

Table 2 Nursing homes (continued)

| Article | Type of study | Focus article | Findings |
|-------------------------------|---|---|---|
| Ward-Griffin et al. 2003 [31] | Empirical, interviews with family-nurse dyads (17). Canada | Insight into the relationship between family members and nurses on a long term care ward and on how to improve this relationship. | There are different types of relationships between nurses and family members. It is important that the approach is family-centred, family members should be given the opportunity to participate or not. |
| Isola et al. 2003 [32] | Empirical, survey amongst family members (624). Finland | Report on the quality of care as evaluated by family members. | Family members are very satisfied with care in general. Family members can play an important role in the care process. Most of them felt they had been adequately informed, given opportunities for participation and support. A minority felt they received too little information, participation possibilities and support. |
| Rosen et al. 2003 [33] | Empirical, focus groups and survey amongst family members (18). US | A web based system of interactive video training was tested to enhance family participation in nursing home care. | Family members have a difficult position. Their participation in care can be important. Family members have too little knowledge to participate well, the computer based videos can help them gain such knowledge. |
| Hertzberg et al. 2003 [34] | Empirical, interviews with nurses (19). Sweden | Exploration and description of nurses views and experiences of relatives of residents who live in nursing homes. | Relatives were seen as a resource and nice although demanding. The nurses saw relatives as part of their work; a part that could be time consuming and had low priority. The relationship could be improved. |

Table 2 Nursing homes (continued)

| Article | Type of study | Focus article | Findings |
|----------------------------------|--|--|---|
| Cohen-Mansfield et al. 2003 [35] | Empirical, physicians (6) and nurse practitioners (3) completed questionnaires that described medical decision making processes for 70 residents. US | Description of the medical decision making process. One of the actors mentioned who play a role in this are family members, this is not the special focus of the article. | Family members are seen as representatives of the residents and they are often mentioned together. |
| Looman et al. 2002 [36] | Empirical, interviews with nurse assistants (114). US | Focus on nurse assistant reports of both positive and negative behaviours exhibited by family members of cognitively impaired residents. | Nurse assistants want to be treated nicely and with respect by family members. They derive satisfaction and good feelings from seeing that family members remain involved. Lack of involvement is a source of great distress to nurse assistants. |
| Lindgren et al. 2002 [37] | Empirical, survey amongst family members and nurses (36). Sweden | Focus on the degree of agreement between nursing home staff and families in assessing the needs of cognitively impaired nursing home residents. | Family members agree with staff on most of the needs of the resident, but disagree in their assessment of some aspects of physical functioning and privacy and boredom. Family members perceive them as bigger problems than nurses do. |
| Hertzberg et al. 2001 [38] | Empirical, interviews with family members (28). Sweden | Exploration and description of the experiences of relatives in the next generation to that of older persons living in nursing homes regarding their interactions and relationships with staff. | Family members are positive about the care in general but identify some problems in communication. They need to take initiative for communication themselves. They want more information to be delivered spontaneously. |

Table 2 Nursing homes (continued)

| Article | Type of study | Focus article | Findings |
|----------------------------|---|--|--|
| Hertzberg et al. 2000 [39] | Empirical, focus groups with relatives and staff. Sweden | Description of relatives' and staffs' experiences of each other in their relationships. | Some family members do not get the right and complete information; they find it difficult to get the proper information. Staff was sometimes unsure about what information to share with relatives (for instance information that relatives may find shocking), they also were unsure about how to support relatives, a lack of knowledge and skills was identified. |
| Gladstone et al. 2000 [40] | Empirical, interviews with family members (27) and observations of care. Canada | Exploration of how families perceive their relationships with staff. | Family members appreciate it when care and attention is given to residents and themselves, when they are informed and when they are given opportunities to engage in joint problem solving. They actively try to get along with the staff. They want the relationship to be like teamwork. |
| Pillemer et al. 1998 [41] | Empirical, survey and interviews with family members and staff. US | Study of an intervention (partners in caregiving program) to prevent communication problems. | Family members and staff should be partners; the initiative can help in improving this relationship. |

Table 3 Mental health care

| Article | Type of study | Focus article | Findings |
|----------------------------|---|---|--|
| Schmetzer et al. 2008 [42] | Descriptive US | Presentation of a possible mechanism for increasing communication about psychiatric matters between physicians and families of persons with mental illness through a presentation in the education of physicians. | Some physicians still have concerns about communicating with family members due to issues of patient trust, confidentiality, or left over outmoded beliefs that families either cause mental illness or exacerbate its symptoms. Attention for family members in education can improve this. |
| Berman et al. 2008 [43] | Descriptive US | The importance of teaching residents to think family as part of core competencies. | Involving family members results in improved patient outcomes. There is however too little attention for family members. Autonomy is incorrectly seen as precluding family involvement. |
| Langlands et al. 2008 [44] | Empirical, survey amongst mental health consumers, carers, clinicians (157). International panel | Development of a guideline on how a member of the public could help someone who may be experiencing psychosis. Family members are mentioned in the article but not the special focus. | Family and friends can be important facilitators of pathways to professional care. They lack necessary skills and need training to intervene effectively. |
| Endrawes et al. 2007 [45] | Empirical, interviews with family members (7). Australia | Exploration of the experience of Egyptian families caring for a relative with mental illness in Australia. | Having a mentally ill relative has a large impact. People report a lack of information, involvement and support of health care professionals. |

Table 3 Mental health care (continued)

| Article | Type of study | Focus article | Findings |
|---------------------------|---|---|---|
| Goodwin et al. 2007 [46] | Empirical, focus groups with carers. Australia | Description of carer experiences and understandings of participation in mental health care. | Carers experiences vary; they are both positive and negative. Family members are not always listened to, receive little information and support. There are differences between nurses in how they work with family members. |
| Maheux et al. 2006 [47] | Empirical, survey amongst physicians (255). Canada | Documentation of with whom family physicians communicate when evaluating adolescents with mental health problems, to whom they refer and their knowledge about accessibility of mental health services. Focus not specifically on family members. | Although most family physicians had communicated with parents at least once during the last year, few did so routinely. Confidentiality is raised as a possible explanation. Contacts are important since families can provide more information. |
| Clarke 2006 [48] | Empirical, report of experiences mother. UK | Description of contacts with staff. | Experienced many problems, little information exchange, and little regard for her situation. Felt that staff cannot deal with proactive family members. Has not experienced similar problems outside mental health care. |
| Jakobsen et al. 2006 [49] | Empirical, interviews with parents (12) and literature review. Norway | Exploration of how parents of adult psychiatric patients experience collaboration with health professionals in community health care. | Health professionals do not want family members to be involved and do not inform, consult with or support family members. Professionals' attitude to confidentiality frustrates parents most, however not all professionals deal with it so rigorously. |

Table 3 Mental health care (continued)

| Article | Type of study | Focus article | Findings |
|--------------------------|---|--|--|
| Clearly et al. 2006 [50] | Descriptive Australia | Description of the challenges of facilitating carer participation. | Interaction with carers in a respectful and collaborative manner and providing information and support is an essential part of modern mental health service delivery. There is a lot of staff confusion in the area of confidentiality and privacy. Confidentiality can be an excuse for not working with carers more actively. There are also time constraints. |
| O'Connell 2006 [51] | Descriptive US | Description of the needs of family members and the role nurses can play to help them. | Dealing with family members is part of the nurses' job. Family members also suffer and need support. Providers are sometimes reluctant due to confidentiality and some continue to view family members as causative factors. |
| Gavois et al. 2006 [52] | Empirical, interviews with family members (12). Sweden | Development of a model of support based on the needs of families. | Family members play an important role, the effects on them are large and they need support. Family members who are supported and who were included in the care process perceived less stress. |
| Truman 2005 [53] | Literature review | Exploration of the effects of a more active role of patients and family members on the autonomy of the professional. Contacts with family members are not the central focus. | Family members and patients are mentioned together. Being a carer can have a toll on the individual, it is important that they are involved. Carers and professionals can think differently about the care that is provided. |

Table 3 Mental health care (continued)

| Article | Type of study | Focus article | Findings |
|---------------------------|--|---|--|
| Wynaden et al. 2005 [54] | Empirical, interviews with primary carers (27). Australia | Exploration of how patient confidentiality issues impact on carers. | Carers are expected to undertake the caring role with little support. Lack of collaboration with professionals increases level of distress. Confidentiality was one reason why professionals were unwilling to collaborate. |
| Resnick et al. 2005 [55] | Empirical, survey amongst clients (902). US | Exploration of correlates of informal and formal contact between clinicians and families of individuals with schizophrenia. | There is little contact between families and clinicians. |
| Harden 2005 [56] | Empirical, interviews with parents (25). UK | Description of experiences of young people with mental health problems. | Parents find it difficult to deal with the situation. They feel they are blamed by professionals. When their child turns 16 parents are formally excluded because of the privacy of the patient. |
| Sjjoblom et al. 2005 [57] | Empirical, focus groups (4) with nurses. Sweden | Examination of nurses' views of the family in psychiatric care. | Nurses acknowledge that family members are in a difficult position, that they need support and that it is important to exchange information. However they rarely involve families. Time constraints and the autonomy of the patient are considered to stand in they way. |

Table 3 Mental health care (continued)

| Article | Type of study | Focus article | Findings |
|-----------------------------------|--|--|---|
| Jeon 2004 [58] | Empirical, interviews with nurses (6), family caregivers of older people with depression (7) and observations. Australia | Examination of the processes through which community mental health nurses work with families of older people with depression. | The importance of support for and involvement of family members is often not recognised. It is important to shape mutuality to make family members an integral part of care. |
| Strengler-Wenzke et al. 2004 [59] | Empirical, interviews with family members (22). Germany | Description of how relatives of people with OCD experience stigmatisation and discrimination in their everyday lives. | Family members are greatly affected because of burden of care and stigmatisation. They receive little support and information from professionals. Confidentiality is used as a reason not to inform them. This leads to insecurity about how to deal with the illness. |
| Rose et al. 2004 [60] | Empirical, focus groups (11) with families, patients, and health professionals. US | Identification of barriers to family care in psychiatric settings, description of family and provider perspectives about what constitutes effective family care. | Current health policies do not show endorsement of a family care approach. Professionals report a lack of training and resources. Family members want improved communication and feel that this does not have to be time consuming. Confidentiality issues were also an alienating factor. |
| Marshall et al. 2003 [61] | Empirical, survey amongst providers (59), family members (68) and interviews with providers (8). US | Examination of how providers and family members interpret and implement confidentiality policies about the release of information to families. | Providers interpreted confidentiality policies very conservatively. There is a lot of confusion about what type of information is confidential. A minority feels legislation does not stand in the way of informing families. The situation poses a barrier to collaboration between providers, consumers and family members. |

Table 3 Mental health care (continued)

| Article | Type of study | Focus article | Findings |
|------------------------|---|--|--|
| Kaas et al. 2003 [62] | Empirical, survey amongst professionals (31). US | Identification of experienced barriers to collaboration with families by mental health professionals. | Reported barriers are: lack of time, feelings of conflict about treating the patient vs. the family, beliefs that involvement may be harmful, lack of visible results of the benefits, loss of hope with the family, stigma, feelings of guilt, client not wanting the family to be involved, difficulty of family members in communicating with the client. |
| Meer et al. 2002 [63] | Opinion article US | Description of the conflict that many clinicians are likely to face with regard to confidentiality when working with clients from south Asia. | Confidentiality is the most important norm in relationship (aside from do not harm) between clients and psychologist. However the subject of confidentiality is dealt with differently in different cultures, professionals need to recognise this. |
| Riebschleger 2002 [64] | Empirical, survey amongst professionals (73). US | Exploration of the initial assumptions of community mental health professionals to a practice simulation vignette concerning the role of the family. | Many professionals acknowledge that a mental illness has negative consequences for family members and that family members are positive treatment resources. A minority feels that family members can play a negative role. |

Table 3 Mental health care (continued)

| Article | Type of study | Focus article | Findings |
|---------------------------|---|---|--|
| Marshall et al. 2000 [65] | Empirical, survey amongst family and consumer members of the National Alliance for the Mentally Ill. US | Examination of the process of releasing information to families and the types of information they receive. | The majority of family members received general and some specific information. Few received information about the treatment plan. A large minority (41%) did not receive general information. Most of them were told this information was confidential. Few consumers were asked their permission to release information to their families. Most consumers felt it was important that their family was involved. |
| Wuerker 2000 [66] | Literature review | Review of research revealing a unique vulnerability to stress in persons with schizophrenia and suggesting that communication difficulties with family members may be due to a shared genetic heritage. | Previously it was felt that family members were the cause of mental illness. After that expressed emotion research implicated accused family members. This article explores biological causes. Nurses need to be aware of biological knowledge so they can communicate better with family members. |
| Srebnik 1999 [67] | Descriptive US | Description of types of mental health advance directives. No special focus on family members. | Advance directives can improve communication with family members since they can ensure agreement about their role. |

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CHAPTER SEVEN

THE LIMITS OF PATIENT POWER

An active role of patients in health care is part of a more general trend in mostly Western societies to attribute a more active role to citizens in various aspects of social life. This active role for individuals is translated to health care through government policies that aim to democratise and increase the effectiveness of health care decision-making and services. In Dutch health care there is an especially strong focus on activating the patient on both the individual and collective level. Patients are expected to participate actively in all kinds of decisions concerning their care, including choosing their provider and insurer and making informed decisions about their treatment. Furthermore, before turning to the professional health care system, they are expected to organise their own care in their social network first, which activates individuals in their network as well. Through their organisations patients can also participate in decision-making on subjects such as health research, guideline development and policy-making by institutions, insurers, municipalities and the national government.

This thesis explored how this policy works in practice and what its consequences are by focussing on participation on the collective level (mostly through patient organisations) and the individual level (by focussing on mental health care). Although this policy has certain advantages, this study concludes that there are limits to patient power, which can be established empirically. On the basis of these findings the normative claim can also be made that there should be limits to patient power.

Based on the empirical findings this chapter elaborates on the effects of this policy on patients and their carers on both the individual and on the collective level and identifies a number of tensions. The chapter reflects on whether patients have actually become more powerful and if they should become more powerful. It concludes with recommendations for policy-makers, patient organisations and researchers.

Not everyone can participate

This study makes clear that not everyone can or wants to take an active role in the organisation of their care. For certain groups in society participation in various aspects of individual care is especially difficult. Although it is likely that the participation possibilities have an empowerment effect for those who are able to use them, the case of mental health care, described in Chapters five and six, shows that for patients who are not able to capitalise on these possibilities, they can even be disempowering. Another important point with regard to who participates is the fact that in the current situation certain other actors that can be considered stakeholders also suffer negative consequences from this policy. The case of family members of mental health care patients highlights this point. They have been shut out of the professional care process because of the strong focus on patient autonomy and confidentiality. These effects may give cause to reconsider who should be the focus of health care

and considered legitimate stakeholders (cf. Van der Lyke 2000).

On the collective level, described in Chapters two, three and four, the same mechanism is identified. Some patient organisations can perform all the activities expected of them by policy makers but there are also many that cannot. The opportunity structure offered to patient organisations is also important in this regard. Patient organisations are given the opportunity to participate in the neo-corporatist decision-making structure in Dutch health care, which means they are asked to participate in formal decision-making procedures with the other actors in health care (Chapter 4). However, not all patient organisations are able to participate in such a structure; it shuts certain groups out given that it puts high demands on organisations. Furthermore, the way participation is shaped on the collective level raises the issue of representativeness and accountability of these organisations. For example, the active participant needs certain skills and knowledge to be able to participate, skills and knowledge which the 'average patient' does not have. The input of patient organisations therefore largely depends on the active volunteer or professional employee who participates in a certain decision-making process thus leading to the question of whose interests are represented.

Civil society organisations, such as patient organisations, are not necessarily democratic since they can favour certain groups of people (cf. Hooghe 2002; Skocpol 2003). Patient organisations are no different in this regard. The increased emphasis on the role of umbrella organisations exacerbates the representativeness issue. This is because these organisations, run by professional employees, are further removed from patients themselves due to their position in the patient movement. The situation in mental health care described in Chapters five and six shows that the ideal the patient movement fought for – the patient as an autonomous individual capable of making his own decisions – does not work out well for all patients. Importantly, this very patient movement also consisted of relatively highly educated empowered (former) patients (Oosterhuis and Gijswijt-Hofstra 2008). This makes it all the more questionable whether organisations comprising such an active membership can represent all patients.

Redistribution effects

On both the individual and the collective level patients have difficulty in fulfilling the active patient role. This not only causes the interests of certain patients to be represented poorly but can also have a negative effect on the quality of care they receive. The case of mental health care shows that this policy can even have the perverse effect of *weakening* the position of severe mental health patients and decreasing their quality of care. Although mental health care can be considered one specific sector in health care it is similar enough (for instance there are large groups

of vulnerable patients in other sectors as well, such as the elderly or people with an immigrant background) to serve as a warning for health care in general, since it can lead to quality differences between the people who can take on this active role and those who cannot.

The situation on the collective level again raises similar problems, which causes the goal of increased quality of decisions to come under pressure. The incorporation of patient organisations in a neo-corporatist decision-making structure allows patient organisations access to all kinds of decision-making procedures. However, as this study points out, not all organisations can become active in all the decision-making processes this structure offers and this could cause redistribution effects between patient groups that can participate and those that cannot. In addition, in the case of the groups that can participate it is often unclear whether they actually influence the decision-making process. If not, then neither the goal of increased quality of decisions nor the goal of democratic decision-making is reached (Chapter 4).

Ironically, patient participation could also redistribute power to the actors that organise their participation. An important question of participation programmes is whether they challenge or reinforce power relations (Lister 2007). This study shows that patient organisations can participate but often have no influence on the decisions. Meanwhile the actors that offer the possibility of participation can claim that their decision-making is better, since the patient's perspective is taken into account, and democratic and therefore more legitimate as well. In actual fact, patient participation is merely instrumental for other actors in health care in such a situation. This goes for such actors as providers and insurers and the government as well. The government influenced patient organisations' activities, organisational structure and even their ideology through subsidising them and opening up all kinds of decision-making procedures to them (Chapter 3). The conclusion is that neo-corporatist decision-making in this policy area has additional disadvantages compared to decision-making in the socio-economic policy sphere where it was originally established and where problems such as having to seek consensus (and therefore be satisfied with less than ideal outcomes) and representativeness issues are reported.

The combination of different goals, levels and perspectives

The two goals that patient participation is supposed to serve – making health care more democratic and more effective – are not unambiguously found in practice and participation can actually have negative effects on both. Besides the fact that the goals of participation are not fully achieved, there are identifiable tensions between different goals, levels of participation and the perspectives of actors, which also warrant attention.

Tensions between different goals

Participation is supposed to serve different goals, both practical and ideological, and this complicates the debate on participation. Patient participation has a large ideological appeal since it is deemed only right to let those affected by decisions that concern such an important aspect of their lives participate. This ideological appeal is then combined with the more practical argument that it will raise the quality of decisions. The combination of these arguments makes it hard to argue against participation. When it cannot be shown in practice that quality is raised, the ideological appeal leads to the conclusion that more effort should be made to make it a success. Examples of this are shown in the literature on patient participation in guideline development (Chapter 2), in policy documents (Chapter 3) and in the opinion of patient organisations (Chapter 4). This intertwining of arguments has caused the debate to go into just the one direction, leaving alternatives unexplored and disregarding the negative effects discussed above.

This study shows that the increased effort is most often asked directly of patients and their organisations (Chapters 2, 3 and 4). Patients and their organisations need to professionalise, otherwise they are not taken seriously by other actors and cannot contribute to complicated discussions, thereby defeating the goal of effective participation. However, professionalisation estranges them further from their constituency (patients suffering from a certain condition), which can be valued negatively from a democratic perspective since it delimits their ability to truly represent patients. Moreover, while the participation *process* may become more effective since participants can contribute to complicated discussions, the *outcome* of the process, better quality decisions, also comes under pressure since the input participants were originally asked to deliver, their experiential knowledge, is pushed to the background. Thus the goals of participation do not necessarily coincide and their intertwining results in a dynamic which turns the practice even further away from the policy ideal.

Tensions between different levels

There are identifiable tensions between the different levels of participation. On the individual level it is continuously emphasised that health care should become more attuned to individual patient preferences, but on the collective level representatives of patient organisations are expected to contribute a homogeneous picture of what 'the patient' wants in discussions. Evidently the individuality of patients is no longer important on this level. While it is argued that individuals need sponsors such as patient organisations to ensure that their interests are taken into account since it is recognised that individual patients cannot do this alone; multilevel participation does raise new problems.

How participation is shaped on the collective level adds to this problem. The professionalisation of patient organisations also causes them to move away from actual patient experiences, the input originally felt to be important which, as an additional perspective to those of professionals and researchers, could improve the quality of decisions. When patient organisations professionalise in such a way that they have similar knowledge to professionals and researchers their perspective contributes less to the discussion and makes the claim that the patient perspective is already taken into account even further off the mark (Chapters 3 and 4). Patient participation on the collective level could even hamper the individual patient to influence his care since it raises the suggestion that the patient's perspective has already been taken into account (Chapter 2).

Secondly, tensions between aspects of the active citizenship policy have become apparent in health care. One focus of active citizenship – the importance attached to informal care to be provided by individuals in the patients' network – clashes with the emphasis on the individuality of the patient and patient autonomy as is shown in the case of family members of mental health patients (Chapters 5 and 6). Although this policy also calls upon individuals to become active, for example, in taking care of their loved ones, it also focuses on citizens or patients in their social network (Sevenhuisen 2000; Van der Lyke 2000). This acknowledgement of the importance of a patient's social network is, however, not reflected in mental health care in its view towards the patient. This puts family members in an ambiguous position. On the one hand they are expected to care for their sick relative and on the other hand they get shut out of the formal care process since patient autonomy is regarded so highly. Thus these family members are not recognised as legitimate stakeholders who should be involved in the professional health care process.

Tensions between the perspectives of different actors

Whether to regard certain effects of the active patientship policy positively or negatively also depends on the perspective of the chosen actor. For instance, from the perspective of government, patients and their organisations have proven a successful steering mechanism (Chapter 3). The analysis of government documents and research into patient organisations shows that they were used to act as a countervailing power to health care professionals and insurers. The government offered patient organisations access to all kinds of decision-making procedures, thus giving them many opportunities to participate in decision-making. However it also put them at risk to be used instrumentally, since government and other parties can use their participation for their own purposes. The different goals cause tensions in this regard as well. In terms of effective decision-making, governmental influence can be valued positively from the government's perspective. However, it does raise concerns about

how much government influence on civil society is desirable from a democratic point of view.

The case of family members in mental health care shows that similar processes take place on the individual level where the actual care process takes place (Chapters 5 and 6). At first sight, emphasising the autonomy of the patient and his right to make decisions could be valued positively from the perspective of the patient since it can be empowering and give him more control. It can also be valued positively from the perspective of the professional since he does not have to deal with family members, who can be considered difficult, as well. It does put family members in a very difficult position though. Moreover, this study shows that the effects in practice can eventually be valued negatively from the perspective of patients and professionals since it can decrease the quality of care.

A more powerful patient?

This research concludes that the patient activation policy has presented opportunities for increasing the empowerment of patients in health care. However, the study also shows that it is questionable whether the positive results expected from this policy are attained in actual practice. There are cases where the policy actually results in negative consequences for patients and other stakeholders. More participation does not necessarily have an accumulative positive effect. It is therefore important to acknowledge the limits of patient power. The empirical data show that patients and their organisations are not equipped to fulfil all the expectations of policy-makers. Although it is argued that this will change when participation opportunities are increased and intensified, patients and their organisations will always remain in a dependent position and that makes it unlikely that they can become a truly equal party. Policy-makers and other actors give the empowerment opportunities which means that there is always some steering going on. Furthermore, patients must depend on these other actors to use their input or not, they have little opportunity to enforce compliance to their views.

The findings also lead to the conclusion that there should be limits to patient power. Focusing too much on patient power can lead to important negative effects, such as inequality, instrumental use and the disregard of certain interests. A broader view to health care and the patient than just individual rights and responsibilities is important (cf. Mol 2006; Zuiderent-Jerak 2007). The strong focus on patient power does not do justice to the dependent position of patients, the condition they suffer from and their embeddedness in their social context (Mol 2006). Therefore, the case of limiting patient power can also be put forward from a normative point of view.

However, patient participation or patient power should not be abandoned altogether. We should not turn back to a situation where the patient passively depends

on the health care professional to know what is best for them. People who can and want to actively participate in their care should have the opportunity to do so. But this should not become an imperative dutifully imposed upon all individuals and patient organisations at all times. Focussing on individual patients also means that attention should be paid to their individual ability and wish to become active or not. It is important not to think in generic terms about patient participation.

This also applies to the methods used for participation. More possibilities and more intensive methods are not necessarily better. Patients can indeed point out ways to improve health care on the basis of their own experience. However, the form of this policy seems to matter. Participation opportunities that stay close to patient experiences, such as mirror conversations and research into patient preferences seem to offer important insights (Bate and Robert 2004; De Wit et al. 2008). This study found that other intensive forms of participation, such as in formal decision-making procedures, do not work well in practice. But more research is necessary about what actually works and what does not.

Implications of the study

The introduction of this study identified a notion commonly held by policy-makers, patient organisations and researchers alike, the notion that the policy of attributing more activities to patients should be the way forward. The ideological appeal (it is only right to give patients a say in health care decisions that concern their personal life so profoundly) in combination with the more practical appeal (it will lead to better decisions and a more efficient health care system) makes it hard to disagree with. Several actors seem to have internalised this way of thinking. For example, patient organisations call for more participation possibilities in a system many already find difficult to participate in (Chapters 3 and 4). Also, health care professionals in mental health care have internalised the idea of autonomous patientship in a way that makes it very hard indeed to resolve such negative consequences as shutting out family members (Chapters 5 and 6).

One implication of this internalisation is that it makes it hard to change the course of policy. However, it is important to realise and address the fact that *more* participation and *more* ways of participation do not have a cumulative positive effect. There are limits to participation and it is important that these are recognised since too much emphasis on patient power and the autonomy of the patient can have negative effects, as described in this study. The following implications for policy-makers, patient organisations and researchers can be identified.

Implications for policy-makers

It is crucial that policy-makers do not regard active patientship as a miracle cure for

problems in health care that will simultaneously and automatically ensure democratic decision-making and effective policy-making. It does not always work in every situation or for every person. Patients (or their representatives) should be able to choose whether they will take an active role or not; participation should not be a duty or imposition. It is also vital to acknowledge that there will be cases where patient participation is not a good idea or other methods of participation should be used to accomplish certain goals. Furthermore, patients may have legitimate reasons for opting out of participation (Trappenburg 2008). It is important that policy-makers acknowledge these reasons. Being allowed to opt out also fits the empowerment ideal, since the choice not to become active can also be considered a form of empowerment.

It is essential not only to recognise that this policy has negative effects, as outlined in this study, but also to develop policy that overcomes such problems. Examples where policy could help address problems in practice include but are not limited to: strengthening the position of family members, critically reflecting on where participation of patients is important and finding a balance between the responsibility of government, professionals, family members and patient in various situations. Depending on the situation and types of problem, representation of patient interests can and should be carried out by other actors than the patient. This would include family members, health care professionals and Parliament. Patients should not be expected to always have to do this for themselves.

Also, policy-makers should treat interference with civil society organisations, such as patient organisations, with reservation. Too much interference with these types of organisations can be evaluated negatively from a democratic perspective.

Implications for patient organisations

Implications for patient organisations can also be distilled from the results of this study. Although participation in decision-making is an offer difficult to refuse, it is an option that can and should be given critical consideration. Participation often does not result in influence (and when it does it cannot be ensured that patients are truly represented), but instead serves the goals of other actors. Patient organisations should therefore think twice about whether they want to participate in the process. It is important for them to think critically about which subjects are truly important for their members and act on those instead of busying themselves with all the policy commotion.

Patient organisations can also return their primary focus back on the activities they were originally founded for: providing peer support and information to their members, which can be important to strengthening individual patients who want to perform an active role in their care process, or to help patients deal with their condition in daily life. Although interest representation has become such an important part of their work, influenced by government policy, it may not be the most important one.

Implications for future research

As stated above, active patientship policy is very broad and participation methods and opportunities seem almost endless. It is important to learn more about what works and what does not and to explore other aspects of this policy. Furthermore, more research is necessary into how the various aspects of this policy interact with each other.

Although other actors in the field were interviewed, most interviews were conducted with patient organisations and family members. For a more complete picture it is important to study the experiences of the other actors in more depth as well. Moreover, as yet little is known about what individual patients, their social network, and future patients think of the policy expectations and how they experience the activities that they are supposed to perform. Qualitative research can offer important insights into the actual behaviour of patients, the reasons behind it and its effects. The same goes for the experiences of health care professionals. Still little is known about how they evaluate this policy and how they evaluate the effects of patient participation.

One more essential subject to study in more depth concerns the effects of the unequal ability of patients and their organisations to perform the active patient role. This study indicates that this could lead to quality differences and differences in the way certain groups are represented. How these differences actually work in practice should be researched further to enable better policy evaluation. This is important since these differences could undermine one of the central values of the Dutch health care system; equality.

Another interesting point for further research is the ties between government and other civil society groups. The case study on the strong ties between government and patient organisations raises important issues from the perspective of democratic decision-making and the limits of government intervention in civil society. It will be interesting to see if similar ties can be seen between government and other civil society organisations in a time when the importance attached to such organisations has increased.

Concluding remarks

In conclusion, all actors in the health care field should recognise the limits, advantages and disadvantages of patient participation. They should look critically at where and when patient participation is important and what form it should take. It is important to identify where other actors should step up and take responsibility and become active. Limiting patient participation means that the patient should not be made responsible for every aspect of his care. It is vital to remember that patients are not consumers and citizens only but patients as well. Setting limits is important in order to really strengthen the position of patients and provide them with good quality care.

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Summary

Dutch health care policy attributes an active role to patients in health care decision-making. Patients are supposed to make informed choices of health care providers and insurers, decide on their treatment together with their health care professional and organise their own care by asking family members to provide informal care. In addition they are supposed to become active in their health care institutions' client council and patient organisation. In this way they can participate in decision-making on all kinds of subjects such as the policy of their health care institution, the medical guideline for the condition they are suffering from, the medical research agenda and the health care policy of national and local government. This thesis studies the experiences gained with the active role of patients in practice.

Chapter 1 describes the policy trend of active citizenship. The policy of activating the patient in health care is part of a broader tendency to activate citizens. Policy-makers in many Western countries expect citizens to become active both on the individual and the collective level. The activities expected from citizens are three-fold. First, citizens should take responsibility for themselves and play an active role in their use of public services. Secondly, citizens should take care of each other, for instance by doing volunteer work. Thirdly, citizens should perform activities to improve public policy and services in general. There are high expectations for what this policy should accomplish, including making decision-making and public services more democratic since it should give citizens the opportunity to influence decisions that affect them and it should raise people to be good citizens. It should also make decision-making and public services more effective since it should save costs, provide tailor-made services, as well as improve the quality of public service policy.

All these activities and expectations come together in the Dutch health care system. Besides the high expectations there is also criticism of this policy. It will have negative consequences for people who cannot take on an active role and it will undermine the solidarity of the system. Since little is known about how the policy is working in practice this thesis studies this subject. This thesis has formulated the following research question: What experience has been gained in implementing active patientship policy? Are its goals being achieved in practice and can patients take on the active role expected of them? The first part of this thesis concentrates on participation on the collective level. The second part focuses on the individual level.

Chapter 2 studies the experiences with patient participation in guideline development on the basis of an international literature review. This chapter shows that

there is consensus in the literature about the importance of patient participation in guideline development and this is increasingly being put into practice. At the same time, however, the review shows that its added value has yet to be established. The conclusion of existing research into the subject is that patients *can* participate provided they are given the proper training and support. Thus, the articles included in the review conclude, patients *should* participate in guideline development. This chapter questions this conclusion. The research into guideline development practice exposes certain difficulties. For instance, it puts high demands on patients, who find it difficult to contribute to discussions with health care providers and researchers (the other participants in the development groups). When patients do contribute it does not necessarily mean that their input will be used. The last problem is a consequence of the fact that it is difficult to integrate patient experiences into an otherwise evidence-based guideline. The literature review shows that the expectation that guideline quality will improve when patients participate cannot be established empirically. Furthermore this chapter argues that ironically the danger is that health care could become less patient-centred as a result of participation on the collective level. When the suggestion is raised that the patient perspective is already incorporated into the guideline, chances are that this could become an excuse for the users of the guidelines not to pay as much attention to patient preferences at the individual level. Although the intrinsic value of participation can be reason to continue participation practices, it is argued that the fact that the extrinsic goal, better quality decisions, is not reached should be reason to reconsider these practices.

Chapter 3 focuses on Dutch government policy directed at patient organisations, based on an analysis of policy documents and research into patient organisations. The Dutch government holds high expectations for patients' interest representation. To facilitate interest representation activities the government has been subsidising such organisations ever since the 1980s. The government has attributed the official 'third party' role to patient organisations. Patient organisations are recognised as a legitimate partner and have been given access to the neo-corporatist decision-making structure of Dutch health care. As a result patient organisations are participating in all kinds of formal decision-making processes. Internationally speaking, the Netherlands can be seen as a frontrunner in this regard. This chapter shows that Dutch government has not only facilitated this process but has also influenced the organisational structure of patient organisations, their activities and even their ideology. Patient organisations readily make use of their opportunities for participation – this government policy has made them an offer they can hardly refuse. The chapter identifies several advantages and disadvantages of this policy.

The advantages include:

- public accountability is ensured through checks on public money spending;
- patient participation has proven to be a successful steering mechanism;
- patient organisations are given the opportunity to influence decision-making;
- participation can have an empowering effect on those who participate; and
- the policy can prevent undue influence from the pharmaceutical industry.

The disadvantages include:

- the goals of patient organisations are being replaced;
- patient organisations hands are being tied;
- patient organisations have been turned into policy and strategy followers;
- professionalisation has resulted in a loss of empowerment; and
- patient organisations are being put to instrumental use.

This chapter concludes that the situation calls for a change in the course of this policy. Civil society organisations, such as patient organisations, are considered important to the functioning of a democratic state. However, this chapter concludes, too much government interference can prevent patient organisations from playing their attributed role. The government should practice restraint in its relationship with civil society organisations.

Chapter 4 examines the participation of patient organisations in a neo-corporatist decision-making structure in practice. It explores whether the neo-corporatist decision-making structure is a good model of participation. The results stem from interviews conducted with patient organisations and other actors in the health care policy field that have experience with patient participation in their decision-making procedures. The chapter shows that patient organisations have indeed been given an institutionalised position and have many opportunities to participate in formal decision-making processes. Several examples of successful influence by patient organisations are identified. In general, however, patient organisations experience considerable difficulty in influencing decision-making because of their dependent position. In response to this situation, the patient organisations try to professionalise themselves in order to strengthen their position. This chapter concludes that although the neo-corporatist decision-making structure gives patient organisations many opportunities to participate it does not give them an equal position. Many patient organisations cannot cope with the demands. This poses the threat of redistribution effects between organisations that can and organisations that cannot participate. Moreover the dependent position puts patient organisations at risk of being used as instruments. The professionalisation strategy patient organisations use to prevent this raises important issues on representativeness. The conclusion is

that this intensive method of patient participation is not necessarily the best method. This situation calls for further research into when patient participation is truly important and good methods for organising participation.

Chapter 5 shifts the focus from the collective to the individual level and explores the relationship between active patientship policy and of active citizenship of people in the patients' network. Patients have been given an autonomous position in the physician-patient relationship. People in their network, especially family members, are expected to provide informal care. Based on interviews, this chapter looks at the effects of this policy on the relationship between health care professionals and family members in mental health care.

This chapter shows that family members take on important activities as carers and this has a big effect on their lives. It is important that family members and professionals exchange information and that family members get some support from health care professionals. However the fact that health care professionals and family members frame their roles differently prevents this from happening. This has negative consequences for family members as well as for the care of the patient. This chapter identifies the complicated position of family members of mental health care patients as the unwanted result of the emphasis on the autonomy of the patient. Health care professionals in mental health care frame their own responsibilities and tasks solely towards the (autonomous) patient. Patients' family members have no part in that relationship. As a result family members find it difficult to exchange information, consult the professionals and receive support from professionals. Family members frame their role differently. Closely related to the patient, they feel responsible for the patient and his care. Family members identify themselves as fellow-carers to professionals and feel they should be included in the professional care process. This chapter concludes that given the negative consequences of the current situation, mental health care professionals should reframe the role of family members in a way that includes family members in the care process.

Chapter 6 explores the subject of the role of family members in the care process further. Based on an international literature review, the chapter studies how the situation in mental health care compares to other care sectors: oncology and nursing home care. This review shows that the relationship between family members and health care professionals can be a source of problems in varying degrees. Mental health care stands out because of its uneasy relationship between the two actors. Whereas in oncology and nursing homes the implicit assumption in the relationship between family members and health care professionals is that sharing information and consultation is a good thing, in mental health care we find the opposite

situation. This relationship in mental health care is problematic because patient autonomy and confidentiality are regarded so highly in this sector. This chapter goes on to investigate possible explanations for this difference. One of the important explanations is found in the history of the sector in which the anti-psychiatry movement played an influential role. It made the autonomy of the patient a central concept. Most likely this, in combination with the fact that health care professionals are confronted with additional legislation, has caused professionals to strictly adhere to legislation concerning the autonomy of the patient. The literature study shows that another opinion put forward by the anti-psychiatry movement can still be found among mental health care professionals: the opinion that family members (especially mothers) are to be blamed for a patient's illness. This also complicates the relationship between family members and mental health care professionals. The results of this study show that the negative effects of this situation in mental health care may be improved by applying the working methods of professionals in other sectors of care. Also attention should be paid to the possibility of the undesirable effect of a strong focus on patient autonomy and individual interests on family members in other sectors.

Rounding off the thesis, chapter 7 reflects on whether the two goals of the active patientship policy – more democratic and effective decision-making and public services – are accomplished in practice. Most importantly this chapter concludes that although this policy has certain advantages, there are limits to patient power and indeed there *should* be limits because this policy has important negative effects which cause certain tensions. Not everybody and not every patient organisation can play an active role. Moreover, the situation of family members in mental health care shows that the interests of certain stakeholders are not receiving attention. This situation can therefore lead to redistribution effects. The position of those who cannot participate could be weakened. Moreover the instrumental use of participation by other actors redistributes power to these actors. As a result the two goals of active patientship policy cannot unambiguously be found in practice. Besides this, the chapter concludes that the different goals this policy seeks to accomplish do not necessarily coincide and can again cause tensions. The same applies to the combination of participation on the individual and the collective level. The limits of patient participation should be acknowledged so that the patient does not become responsible for every aspect of care. To truly strengthen the position of patients and provide good care, other actors should take responsibility as well.

Samenvatting

In Nederland verwachten beleidsmakers van patiënten dat zij een actieve rol spelen in de gezondheidszorg. Zij moeten geïnformeerde keuzes voor een zorgaanbieder en zorgverzekeraar maken, samen met hun zorgverlener beslissingen nemen over hun behandeling en hun eigen zorg organiseren door mantelzorgers in te schakelen. Daarnaast moeten patiënten ook actief worden in de cliëntenraad van hun zorginstelling en in hun patiëntenorganisatie. Op deze manier kunnen zij meepraten over uiteenlopende onderwerpen zoals het beleid van instellingen, medische richtlijnen, medische onderzoeksagenda's en het zorgbeleid van de nationale en lokale overheid. Dit proefschrift onderzoekt wat de ervaringen met deze actieve rol van patiënten in de praktijk zijn.

Hoofdstuk één gaat in op de achtergrond van het beleid gericht op actief patiëntschap. Dit hoofdstuk laat zien dat deze trend onderdeel uitmaakt van een bredere beleidstendens gericht op het activeren van de burger. Van burgers wordt verwacht dat zij zowel individueel als collectief (in maatschappelijke organisaties) actief worden. Deze activering vindt op verschillende manieren plaats. Ten eerste krijgen burgers meer verantwoordelijkheid voor hun eigen leven. Ook wordt van hen verwacht dat zij een actieve rol spelen en verantwoordelijkheid nemen wanneer zij gebruik maken van publieke diensten. Ten tweede moeten burgers aandacht voor elkaar hebben en elkaar helpen, bijvoorbeeld door vrijwilligerswerk te doen. Ten derde wordt er van burgers verwacht dat zij actief zijn om de kwaliteit van publiek beleid en publieke diensten te verhogen. De verwachtingen van wat dit beleid kan opleveren zijn hoog gespannen. De hoop is dat de activiteiten van burgers besluitvorming en publieke diensten tegelijkertijd democratischer en effectiever maken. Besluitvorming zou democratischer worden omdat burgers de mogelijkheid krijgen om invloed uit te oefenen op beslissingen waar zij de gevolgen van ondervinden. Bovendien zou dit activeringsbeleid een opvoedkundige werking op burgers hebben. Besluitvorming en publieke diensten zouden daarnaast effectiever worden omdat kosten kunnen worden bespaard, diensten kunnen worden aangeboden die beter bij de wensen van burgers passen en de kwaliteit van het aanbod en het beleid kan worden verbeterd.

In het Nederlandse gezondheidszorgbeleid komen al deze activiteiten en verwachtingen samen. Er bestaat echter tegelijkertijd kritiek op dit beleid. Het zou negatieve gevolgen hebben voor de mensen die niet aan dit beleidsideaal kunnen voldoen en de solidariteit van het zorgsysteem zou worden ondermijnd. Aangezien er nog weinig bekend is over hoe dit beleid uitwerkt in de praktijk wordt dit in dit onderzoek nader uitgezocht. In hoofdstuk één is de volgende onderzoeksvraag ge-

formuleerd: Wat zijn de ervaringen met het beleid van actief patiëntschap? Worden de doelen ervan in de praktijk behaald en kunnen patiënten de actieve rol die van hen verwacht wordt spelen? Het eerste deel van dit proefschrift gaat in op participatie op het collectieve niveau. Het tweede deel gaat in op het individuele niveau.

Hoofdstuk twee bestudeert de ervaringen met patiëntenparticipatie in richtlijnontwikkeling op basis van een internationale literatuurstudie. Dit hoofdstuk laat zien dat er in de literatuur consensus bestaat over het belang van patiëntenparticipatie in richtlijnontwikkeling. Bovendien wordt participatie van patiënten in toenemende mate in praktijk gebracht. De literatuurstudie geeft echter ook aan dat de toegevoegde waarde van participatie nog niet bewezen is. De conclusie van de bestudeerde studies is dat patiënten mee *kunnen* praten wanneer zij voldoende getraind en ondersteund worden. Vervolgens wordt daar de conclusie aan verbonden dat patiënten daarom ook (meer) *moeten* participeren. Dit hoofdstuk zet vraagtekens bij deze gevolgtrekking. Onderzoek naar participatie in richtlijnontwikkeling legt namelijk belangrijke moeilijkheden bloot; het kost veel tijd, patiënten hebben moeite om iets in te brengen tijdens discussies met zorgverleners en onderzoekers (de andere deelnemers in ontwikkelingswerkgroepen) en als patiënten iets inbrengen is het maar de vraag of hier ook daadwerkelijk iets mee gebeurt. Dit laatste heeft te maken met het feit dat de integratie van ervaringen van patiënten in de *Evidence Based Medicine* structuur van hedendaagse richtlijnen moeilijk is. Uit de literatuurstudie blijkt bovendien dat empirisch niet kan worden vastgesteld dat participatie van patiënten de kwaliteit van richtlijnen verhoogt. Dit hoofdstuk laat ook zien dat als gevolg van participatie op dit collectieve niveau de kans bestaat dat de individuele patiënt een minder sterke positie in de zorg krijgt, omdat de suggestie wordt gewekt dat het patiëntenperspectief al is opgenomen in de richtlijn. Dit impliceert dat hier minder aandacht aan besteed hoeft te worden in de individuele arts - patiëntrelatie. Hoewel de intrinsieke waarde van participatie reden kan zijn om door te gaan met patiëntenparticipatie in richtlijnontwikkeling, moet het feit dat het extrinsieke doel, verhoogde kwaliteit van besluitvorming, niet behaald wordt reden zijn om participatie in richtlijnontwikkeling te heroverwegen.

Hoofdstuk drie gaat in op het Nederlandse overheidsbeleid gericht op patiëntenorganisaties. Er is een analyse gemaakt van beleidsdocumenten en van bestaand onderzoek naar patiëntenorganisaties in Nederland. De Nederlandse overheid heeft grote verwachtingen van de belangenbehartigingsactiviteiten van patiëntenorganisaties. Teneinde deze belangenbehartigingsactiviteiten te faciliteren heeft de overheid deze organisaties vanaf de jaren tachtig gesubsidieerd. Bovendien heeft zij patiëntenorganisaties de officiële 'derde partij' rol, naast zorgaanbieders en zorg-

verzekeraars, toegedicht. Patiëntenorganisaties zijn daardoor als legitieme overleg-partner erkend en hebben toegang gekregen tot de neo-corporatistische besluitvormingsstructuur van de Nederlandse gezondheidszorg. Zij participeren daardoor in allerlei officiële besluitvormingsprocessen. Deze geïnstitutionaliseerde positie van patiëntenorganisaties maakt Nederland tot een voorloper op dit gebied. Dit hoofdstuk laat zien dat de overheid niet alleen faciliterend is geweest maar ook de organisatiestructuur, de activiteiten en de ideologie van deze organisaties heeft beïnvloed. Patiëntenorganisaties maken gretig gebruik van de mogelijkheden die de overheid hen biedt. Zij hebben een positie gekregen die ze moeilijk kunnen weigeren. Patiëntenorganisaties worden immers toegelaten tot allerlei besluitvormingsgremia waarin zij de belangen van hun leden kunnen behartigen. In dit hoofdstuk komen verschillende voor- en nadelen van deze verregaande overheidsbemoediging aan bod.

Voordelen zijn:

- er vindt verantwoording plaats over publieke uitgaven;
- patiëntenorganisaties zijn een effectief sturingsmechanisme van de overheid;
- patiëntenorganisaties hebben de mogelijkheid om te participeren;
- actieve leden krijgen de kans hun sociaal kapitaal te vergroten; en
- patiëntenorganisaties blijven grotendeels buiten het bereik van de farmaceutische industrie.

Nadelen zijn:

- de doelen van patiëntenorganisaties verschuiven;
- de handen van patiëntenorganisaties zijn deels gebonden;
- patiëntenorganisaties worden beleids- en agendavolgers;
- het *empowerment* effect wordt weer teniet gedaan door professionalisering; en
- de overheid gebruikt patiëntenorganisaties instrumenteel.

Dit hoofdstuk concludeert dat de gevonden situatie om een verandering van de beleidskoers vraagt. Maatschappelijke organisaties, zoals patiëntenorganisaties, geven burgers de mogelijkheid hun belangen te behartigen. Dit is een van de redenen waarom ze worden geacht een belangrijke rol te spelen in het democratisch functioneren van een samenleving. Te veel overheidsbemoediging kan hen deze mogelijkheid ontnemen. Deze resultaten leiden in dit hoofdstuk daarom tot het oordeel dat de overheid een meer terughoudend beleid zou moeten voeren in haar relatie met het maatschappelijk middenveld.

Hoofdstuk vier bekijkt de praktijk van participatie van patiëntenorganisaties in een neo-corporatistische besluitvormingsstructuur. De vraag die hierbij centraal staat is of dit een goede manier is om participatie van patiënten in besluitvorming te organiseren. De resultaten zijn gebaseerd op interviews met vertegenwoordigers van

patiëntenorganisaties. Daarnaast zijn interviews gehouden met vertegenwoordigers van organisaties in het veld van de Nederlandse gezondheidszorg die ervaring hebben met participatie van patiëntenorganisaties in hun besluitvorming. Dit hoofdstuk laat zien dat patiëntenorganisaties veel mogelijkheden krijgen om in formele besluitvormingsprocessen te participeren en een geïnstitutionaliseerde positie hebben gekregen. Er zijn meerdere voorbeelden gevonden waarin patiëntenorganisaties invloed hebben weten uit te oefenen. Vaak hebben patiëntenorganisaties echter moeite om invloed uit te oefenen omdat ze erg afhankelijk van andere partijen zijn. Als reactie op deze situatie proberen patiëntenorganisaties hun positie te versterken door te professionaliseren. De conclusie van dit hoofdstuk is dat participatie in de neo-corporatistische besluitvormingsstructuur patiëntenorganisaties veel mogelijkheden om te participeren geeft. Participatie in deze structuur leidt echter niet tot gelijkwaardigheid. Patiëntenorganisaties zijn geen gelijke partij. Veel organisaties kunnen de vraag niet aan. Het gevaar hiervan is dat dit tot herverdelingseffecten leidt tussen organisaties die daar wel en organisaties die daar niet toe in staat zijn. Bovendien brengt de afhankelijke positie het gevaar met zich mee dat andere partijen patiëntenorganisaties instrumenteel gebruiken. De strategie die patiëntenorganisaties volgen om dit te voorkomen, professionaliseren, roept belangrijke representativiteitsvragen op. De conclusie is daarom dat deze intensieve methode van patiëntenparticipatie niet noodzakelijkerwijs de beste is. Er is nader onderzoek nodig naar hoe en wanneer patiëntenparticipatie het beste in praktijk kan worden gebracht.

In hoofdstuk vijf verschuift de aandacht van het collectieve naar het individuele niveau. In dit hoofdstuk staat de relatie tussen het beleid gericht op actief patiëntschap en gericht op actief burgerschap van individuen in de omgeving van de patiënt centraal. Patiënten hebben een autonome positie in de arts-patiënt relatie gekregen. Van mensen in de omgeving van de patiënt, veelal familieleden, wordt verwacht dat zij mantelzorg verlenen. In dit hoofdstuk kijken we naar de effecten van dit beleid op de relatie tussen professionele zorgverleners in de geestelijke gezondheidszorg en familieleden van patiënten. Dit hoofdstuk laat, op basis van interviews, zien dat familieleden een belangrijke zorgrol vervullen. Deze zorgrol heeft een grote impact op hun leven. Het is daarom van belang dat familieleden informatie en ondersteuning krijgen van professionele zorgverleners. Doordat familieleden en zorgverleners hun rol op een verschillende manier *framen* gebeurt dit echter niet. Dit heeft negatieve gevolgen voor familieleden maar ook voor de zorg aan de patiënt. De moeizame relatie tussen familieleden van de patiënt en de professionele hulpverlening wordt in dit hoofdstuk als een ongewenst gevolg gezien van de nadruk op de autonomie van de patiënt. Zorgverleners beschouwen de zorg voor de autonome patiënt als hun verantwoordelijkheid. Familieleden behoren niet tot hun verantwoordelijkheid en heb-

ben geen rol in deze zorgrelatie. Het gevolg hiervan is dat familieleden van patiënten veel moeilijkheden ondervinden bij het uitwisselen van informatie, het maken van afspraken over de zorg en het vinden van ondersteuning. Familieleden zelf *framen* hun rol op een andere manier. Zij zien zichzelf als collega hulpverleners die ook een taak hebben in het verlenen van zorg aan hun familielid. Daarom zouden zij onderdeel moeten zijn van het professionele zorgproces. Dit hoofdstuk concludeert dat gezien de negatieve effecten van de huidige situatie het gewenst is dat zorgverleners de rol van familieleden *reframen* zodat familieleden onderdeel van het zorgproces worden.

Hoofdstuk zes gaat nader op het onderwerp van de rol van familieleden in. Op basis van een internationale literatuurstudie is onderzocht hoe de situatie in de geestelijke gezondheidszorg zich verhoudt tot andere sectoren van zorg, te weten oncologie en verpleeghuiszorg. Deze literatuurstudie laat zien dat de relatie tussen familieleden en zorgverleners in verschillende mate tot problemen leidt. De geestelijke gezondheidszorg neemt hierin een opmerkelijke positie in. In andere zorgsectoren wordt het delen van informatie en het maken van afspraken positief gewaardeerd. In de geestelijke gezondheidszorg is de situatie omgekeerd. Zorgverleners beschouwen deze relatie om principiële redenen als problematisch. Dit is het gevolg van het belang dat wordt gehecht aan de autonomie van de patiënt en de vertrouwelijkheid in de hulpverlener - patiëntrelatie. Dit hoofdstuk gaat op zoek naar verklaringen voor dit verschil. Een belangrijke verklaring die daarbij naar voren komt is de geschiedenis van de geestelijke gezondheidszorg. Door de sterke antipsychiatriebeweging in de jaren zestig en zeventig van de vorige eeuw is de autonomie van de patiënt een belangrijk concept geworden. Hier wordt veel waarde aan gehecht in de zorgpraktijk. Het is aannemelijk dat dit, in combinatie met het feit dat hulpverleners in deze sector met aanvullende wetgeving te maken hebben, ervoor heeft gezorgd dat zorgprofessionals de patiëntenwetgeving erg strikt interpreteren. Bovendien laten de resultaten van de literatuurstudie zien dat ook het idee dat mensen ziek worden door hun omgeving (vooral door hun moeder) nog leeft onder hulpverleners in de geestelijke gezondheidszorg. Dit draagt bij aan de moeizame relatie tussen familieleden en hulpverleners. De resultaten van de studie laten zien dat dit ongewenste resultaten kan hebben. Daarom wordt aanbevolen om de manier van werken in andere sectoren van de gezondheidszorg over te nemen. Bovendien is aandacht voor de mogelijkheid dat dit neveneffect optreedt bij een te sterke focus op de autonomie van de patiënt in andere zorgsectoren van belang.

Het laatste hoofdstuk bekijkt, op basis van de eerdere hoofdstukken, of de doelen van het beleid van actief patiëntschap, democratisering en toegenomen effectiviteit, in de praktijk worden bereikt. De belangrijkste conclusie in dit hoofdstuk is dat

er naast een aantal voordelen ook grenzen zijn aan de actieve rol die patiënten en hun organisaties kunnen vervullen. Bovendien kan de normatieve uitspraak worden gedaan dat deze grenzen er ook moeten zijn gezien het feit dat zich belangrijke negatieve effecten en spanningen voordoen in de praktijk. Niet iedereen en niet iedere patiëntenorganisatie kan deze actieve rol vervullen. Bovendien laat de situatie van familieleden in de geestelijke gezondheidszorg zien dat niet alle belanghebbenden als zodanig erkend worden. Deze situatie kan tot herverdelingseffecten leiden. De positie van degenen die niet mee kunnen doen kan worden verzwakt. Daarnaast kan door instrumenteel gebruik van participatie de macht van andere partijen juist verder worden versterkt. De constatering is daarmee dat beide doelen van dit beleid niet eenduidig worden behaald in de praktijk. Daarnaast wordt in dit hoofdstuk geconcludeerd dat de verschillende doelen die dit beleid beoogt te bereiken niet zomaar samen gaan en spanningen opleveren. Hetzelfde geldt voor de combinatie van participatie op het individuele en het collectieve niveau. Uit dit alles volgt dat de grenzen van patiëntenparticipatie erkend moeten worden en de verantwoordelijkheid van zorg en zorgbeleid niet altijd bij patiënten moet worden gelegd.

Dankwoord

Een proefschrift schrijven vereist veel van het gedrag dat ook van het onderwerp van deze studie, de moderne patiënt, verwacht wordt. Je moet goed geïnformeerde keuzes maken, voorbereidingen treffen om goed beslagen ten ijs te komen tijdens het consult bij de promotor, stoom afblazen en tips uitwisselen met lotgenoten en in spanning wachten op het oordeel van de experts die het uiteindelijk toch het beste weten. Net zoals de actieve patiënt zijn rol niet alleen kan vervullen, had ik dit proefschrift niet kunnen afronden zonder de hulp van velen die ik op deze plaats wil bedanken.

Zoals de patiënt niet kan zonder goede arts kan een promovendus niet zonder goede promotor. Wat dat betreft besef ik dat ik erg veel geluk heb gehad met mijn promotor Margo Trappenburg. Margo, je hebt me de kans gegeven om na mijn scriptie bij de USBO door te gaan als onderzoeker. Na de eerste onzekere periode die kenmerkend is voor de beginnende academicus heb je me met je snelle, inspirerende, inhoudelijke en praktische commentaar klaargestoomd voor het wetenschappelijk leven. Hoewel de vraag: “wat is nu precies je punt?” op een gegeven moment zeer gevreesd was, heeft me dat geweldig geholpen in het maken van mijn keuzes en het krijgen van een heldere focus. Mijn punt is hier: enorm bedankt voor je geweldige begeleiding.

Jolanda, partner in crime, jou ben ik denk ik de meeste dank verschuldigd. Je hebt mijn werkplezier enorm vergroot. Je hebt me inhoudelijk maar toch vooral met je gezelligheid, humor, vrolijkheid en steun door het serieuze academisch leven heen geloodst. We hebben vaak tegen elkaar gezegd dat we elkaar door het proefschriftschrijvende leven heen hebben geholpen en dat is ook zo. Ik weet nog dat ik mij een keer cynisch afvroeg of dat nu betekende dat we elkaars redding of elkaars molensteen waren. Jij zei toen direct het eerste en uiteindelijk heb je, zoals zo vaak, ook hierin gelijk.

Tijdens mijn zoektocht naar informatie ben ik geholpen door velen. Fonds PGO, ZonMw en Meerkanten geestelijke gezondheidszorg Flevo-Veluwe, stelden de financiële middelen ter beschikking. Ook zonder alle mensen die tijd hebben vrijgemaakt voor interviews en observaties, was dit onderzoek niet mogelijk geweest. Respondenten deelden hun, in sommige gevallen erg persoonlijke, verhalen met mij en ik hoop dat ik hier in deze studie recht aan heb weten te doen. Mijn collega's van de HCG sectie van het iBMG dank ik voor de inspirerende bijeenkomsten in de afgelopen jaren. Ik heb hier veel van geleerd. Dit geldt ook voor de cursussen en bijeenkomsten van de onderzoeksschool NIG en ik dank alle collega aio's met wie ik door de loop der jaren dit traject heb doorlopen.

Kor en Roland, jullie hebben een belangrijke rol gehad in mijn onderzoek door

onze samenwerking in verschillende patiëntenparticipatieprojecten, ik heb hier veel van geleerd. Sam, dank voor het becommentariëren van mijn stukken en het delen van je ervaringsdeskundigheid. Anne, bedankt voor alle praktische ondersteuning en je onmisbare rol op de afdeling door je hulpvaardigheid, mensenkennis en luisterend oor. Mijn kamergenoten door de jaren heen: Berend, Linda, Maartje, Eelko en Esther, jullie maakten het werken in Rotterdam leuk en vrolijk. Saar, ik heb veel plezier beleefd aan onze gedeelde overtuiging dat zoals de patiënt niet alleen zijn fysieke klacht is, de promovendus meer is dan zijn geest, tijdens onze sportsessies, lekkere etentjes en borrels.

Aangezien een mens bepaalde dingen niet zelf kan, moet hij soms zijn grenzen erkennen en experts inroepen. In mijn geval geldt dat voor het ontwerpen van de omslag en de opmaak van dit proefschrift. Marieke, dank dat je mijn expert op dit gebied wilde zijn en voor je prachtige ontwerp.

Ik kijk met erg veel plezier terug op de afgelopen vijf jaar waarin dit proefschrift tot stand is gekomen, mede als gevolg van vrienden en familie die steun geven en het leven leuk maken. Met name belangrijk daarbij zijn Irene, Marieke en Ingvar, jullie zorgen voor de nodige ontspanning en relaxte kijk op het leven. Hans, je bent hét voorbeeld dat keuzes, zoals het schrijven van een proefschrift, tot onverwachte maar prachtige gevolgen kunnen leiden. Dank voor je inhoudelijk commentaar, maar vooral voor je inspirerende, rustgevende, relativerende, liefdevolle en vrolijke levenshouding. Mijn lieve ouders, Michiel en Amber, dank voor het zorgen dat ik met beide benen in de 'normale' wereld blijf staan, met corrigerende teksten als: 'dat woord gebruik je niet in normale mensentaal' en dank voor jullie steun en gezelligheid.

Hester van de Bovenkamp

About the author

Hester van de Bovenkamp was born on November 25th 1981 in Ede in the Netherlands. She studied public administration at Utrecht University between 2000 and 2004. She developed an interest in the role of pressure groups in decision-making writing her MA thesis on the role of such groups in the Dutch transport sector. She was able to pursue this interest further when she started working at the institute of Health Policy and Management of the Erasmus University Rotterdam in 2005, where she studied the role of patient organisations in health care decision-making. In the following years she also did research projects on the role of family members in mental health care, the role of patients in the health care system and the societal and political debate on organ donation. She has published in national and international peer reviewed journals on these subjects. In addition she has also taught and coordinated courses at the institute of Health Policy and Management such as Philosophy of Science, Health care and Democracy and Student Skills.

