

THE POLITICAL PRESENCE OF PATIENTS

Analyzing representative claims

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Introduction

“Gesundheitspolitische Entscheidungen – spielt der Patient überhaupt eine Rolle?” was the title of a conference that took place in Hannover in 2016. I attended that conference one year into my PhD work. The title asks whether the patient (singular) matters to health policy decision making *after all*, or – to translate the title in a figurative sense – whether power holders even take patient preferences into consideration when deciding on key issues in public health policy. The conference was part of a scholarly endeavor within the ever-growing interdisciplinary field of social science research on health and, more particularly, on the role of patients in health policy decision making (Epstein 2008a, 2008b; Rabeharisoa 2003, 2006; Akrich M. and Rabeharisoa 2012; Tritter 2011; Conklin et al. 2015; Gauld 2010; Murphy 2005; Peterson 2001; McCoy et al. 2020; Keizer 2012; Lehoux et al. 2012; Van de Bovenkamp and Zuiderent-Jerak 2015; Etgeton 2009). That endeavor – which could be referred to as *Political Patient Studies* – aims to come to a better understanding of practices that channel patient preferences into political decision making processes. Ironically, political science has contributed astonishingly little to Political Patient Studies.

“Viewed from a longer-term perspective, patients per se have seldom been at the center of health policy” (Garpenby and Nedlund 2020). Taking interest in this phenomenon, scholars from Science and Technology Studies, sociology, bioethics, public health science and further disciplines have examined when, why and how the interests of patients have found their way into health policies – despite the superiority of stronger stakeholders such as health care professionals or insurance companies. They analyzed the political activism of individual patients who seek direct contact with parliamentarians and other political decision-makers, signed online and offline petitions, expressed political opinions on social media, took part in demonstrations, and staged 30-hr sit-ins at departments of health (Anspach 1979; Burden et al. 2017; Christensen et al. 2018). A large and maybe even the largest part of the Political Patient Studies literature focuses on patient organizations (Rojatz 2016; Baggott and Forster 2008; Van de Bovenkamp 2010; Van de Bovenkamp et al. 2010; Epstein 1995; Gerhards et al. 2017; Schicktanz

2015; Rabeharisoa et al. 2014; O'Donovan 2007; Moreira et al. 2014). Patient organizations (POs) are organizations that have been established in many cases *by* and in all cases *for* patients and they provide service and support for those that are affected by the disease they cover. Most POs are multitasking organizations that – as well as political activities – provide peer support, inform patients on current developments in healthcare, organize all kinds of events aimed at raising public awareness for the disease, etc. Their political activism has been observed on the local, federal, national, European and international level (Braunegger-Kallinger et al. 2009; Souliotis et al. 2018; Keizer 2012; Van de Bovenkamp and Trappenburg 2011; Beard 2004). Studies show that POs lobby parliamentarians, organize protests and petitions, engage with mass media, publish opinion statements on (upcoming) legislation as well as reports and papers on pressing issues (Winblad and Ringard 2009; Baggott and Forster 2008; Jones et al. 2004). The political ambitions of POs have been identified as reaching from narrow and exclusively disease-specific goals that benefit a distinct group of patients to broader goals such as preventing further healthcare privatization or improving equal access to healthcare provision (Löfgren et al. 2011; Keller and Packel 2014). Scholars problematize that POs often take part in public hearing processes and sit in advisory, decision making and arbitration boards but still lack any real influence as they are not granted voting rights (Etgeton 2009). Studies on the political activities of POs have helped to identify and distinguish cases in which their activities paid off in terms of contributing to policies that address the wants and needs of patients – and those in which they did not (Rojatz and Forster 2017; Jones and Baggott 2011; Rojatz 2016).

Although the Political Patient Studies literature provides important insights into the practice of making patients matter to politics, it has largely ignored one crucial aspect: namely that of representation. It is here, I believe, that political science has an important contribution to make to Political Patient Studies. Political science has a long and rich history of theorizing and studying political representation (Pitkin 1967; Young 2000; Mansbridge 2003; Rehfeld 2005, 2018; Disch 2008, 2015; Dewey 1927; Williams 2000; Urbinati and Warren 2008; Saward 2010, 2014, 2016; Manin 2009; Eulau and Wahlke 1978), yet unfortunately even key insights and lessons of that scholarship have only

sporadically found their way into the field of Political Patient Studies (Gerhards et al. 2017; Van de Bovenkamp and Vollaard 2018b). In the realm of representation, the “missing political science gaze” (Leeuw et al. 2014) of Political Patient Studies leaves many important questions unexplored. The political activities of POs can be conceptualized as acts of political representation, yet rarely have they been studied through the lens of political science representation theory (Van de Bovenkamp and Vollaard 2017, 2018a). Conceptualizing their political activities as representative acts is justified as POs claim to do what they do on behalf of patients, presenting themselves as protecting, defending, conserving, and enforcing patient preferences and channeling patient interests to politics. What is more, it is not only POs that claim to look out for patients in health policy making. Through the lens of political science representation theory, *non-patient actors* – such as parliamentarians – also come to the fore. Up until now, the literature has been satisfied with accusing (German) parliamentarians of paying too little attention to patients and their wants and needs (Rosenbrock and Gerlinger 2014; Fischer and Sibbel 2011). This accusation, however, lacks empirical basis as scholars have only recently begun to shed light into parliamentary attention towards patients (Nedlund and Nordh 2015; Mold 2013, 2010). Given that parliamentarians are influential power holders whose decisions can shape the lives of patients, we need to know more about whether, how, when, and why parliamentarians render patients politically visible and audible to processes of political decision-making. Adding a representation perspective therefore not only allows us to explore the activities of different actors who claim to represent patients, but also to come to a better understanding of how we should value different attempts to make patients matter to politics.

In this thesis, I will use a representation approach to explore contemporary practices of making patients matter to politics. That is, I am specifically interested in how political patient representation unfolds in practice. I argue that recent and constructivist advances in representation theory, specifically representative claims theory (Saward 2010, 2014; Disch 2019, 2015), are well equipped to guide an empirical analysis of the representation work performed by different actors such as POs and

parliamentarians, with the aim of learning more about whom to listen to when it comes to voicing the political interests of patients – and whom not to.

Theorizing political patient representation

Within political theory, there is no consensus on how to theorize representation (Pollak 2005). The concept of representation has always been the subject of heated debates (see for instance Näsström 2011 and Severs 2010 on constructivist readings of representation; or - most recently Zicman de Barros 2020, 2021 versus Thomassen 2021). When “it comes to representation, one thing, but perhaps only one thing, is undeniable: it is a concept that encompasses an extraordinary range of meanings and applications.” (Runciman and Brito Vieira 2013) Just one or two generations ago, the politics of representation was usually considered to be located in the electoral and in particular the parliamentary arena, concerning essentially the relationship between voters and parliamentarians (Schweber 2016). By stark contrast, representative claims theory, which has dominated the past decade of international representation studies, perceives issues of representation as being *everywhere* (Montanaro 2012, 2019; Saward 2009). While there are still theorists who “would prefer to reserve the term representation to describe electoral representation on the basis of the formal or governmental decisional roles of elective figures” (Saward 2010), proponents of the claims-making account argue that the broadening of our understanding of who counts as representative does not confuse but rather enriches our understanding of “what is going on in representation” (Saward 2010).

I argue that a particular strength of the claims-making account is that it allows an analysis of representational practices of different actors through the same lens. Representative claims theory (Saward 2010; Disch 2011) does not conceptually separate actors in advance but makes it possible to compare and contrast the efforts of categorically different makers of representative claims about patients. In political representation studies, parliamentarians are classic and well-established research objects while POs, as argued above, are not. Interestingly, in Political Patient Studies it is the other way around. POs have received a lot of attention whereas parliamentarians have been largely overlooked.

POs and parliamentarians may (or may not) differ in how they try to make patient interests matter to politics, and representative claims theory helps to detect potential differences by offering theoretical guidance through “the rich plurality of representative practices” (Saward 2010).

Representative claims theory not only helps us to expand our gaze in terms of actors involved, but it also allows the study of dynamic patterns of representation, as it theorizes representation as a process, an activity and a practice. Representation begins with a representative claim that is issued by a (possibly self-acclaimed) representative – such as a parliamentarian, a PO, others NGOs, a neighborhood board, a bureaucrat, a celebrity, a scholar, a religious order, etc (Kuyper 2016; Wolff 2013; Essen and Allen 2017; Saward 2010; Rubenstein 2014; Chowdhury 2019). The making of a representative claim entails the construction of a constituency – such as patients in the case of this thesis. Relying “on their information and imagination” (Celis and Mügge 2018), representatives portray their representees and attribute certain characteristics to them, for instance describing patients as bravely enduring pain. They voice interests that they believe their constituents share, for example claiming that patients desire self-determination in healthcare (Mold 2013). Representation is thus understood to be a process through which representatives render their idea of their representees (meaning their construct of a constituency, in this case patients) politically visible and audible (Ankersmit 2009). Proponents of the constructivist account of representation theory stress that the represented constituency is not a reflection of an entity that exists prior to and independent from being represented (Alcoff 1991; Disch 2015; Saward 2010). They challenge the idea that patients – or any other population that is turned into a constituency – form a unified group with “a fixed, knowable set of interests” (Saward 2010), which representatives can refer to in their representation work. According to the constructivist account, representing does not mean echoing, mirroring or copying. It rather means that representatives create a *political presence* for their constituents according to their perception of them (Ankersmit 2009; Disch 2015; Saward 2019, 2010).

Many scholarly disputes about representation have been about the concept of *political presence* (Castiglione and Pollak 2019). For a long time, the concept of political presence was used to describe

representation as “making present in some sense something which is nevertheless not present literally or in fact.” (Pitkin 1967). However, representative claims theory applies a constructivist reading to representation and consequently problematizes that the concept of political presence misleadingly implies that representation means mirroring or copying. Proponents of the claims-making account stress that “representatives who speak for their constituents are not speaking as the constituents would have spoken” (Brown 2009). Representatives do not *read off* interests, they rather *read in* interests into their constituents (Lord and Pollak 2010a; Lord and Pollak 2010b, 2013). Therefore, representation should better be understood as being about “claims that give the impression of making present” (Saward 2010). It is exactly this “artificial presence by the act of representation” (Runciman 2007) that POs and parliamentarians create for patients that this thesis is interested in.

It is not a given that patients identify with the political presence that has been created for them. Theory stresses that representative claims are made both with and without the approval the representees (Montanaro 2012; Saward 2009). It is neither given that representative claims about patients necessarily contribute to developing health policies that allow patients to live as well as possible with their diagnosis (Nedlund and Taghizadeh Larsson 2016). Practices of channeling the wants and needs of patients to politics are expected to contribute to making health policy decision making better in the sense of resulting in policies that are equipped to address otherwise unacknowledged and unmet needs of patients. However, it turns out time and again that constituent interests channeled are too often generated by indirect means and that even seemingly ‘natural’ representatives who appear trustworthy regarding their constituents’ preferences base their representative claims on rather problematic grounds (Montanaro 2019). For instance, dementia-specific POs, arguably, appear as ‘natural’ representatives of patients living with dementia¹ and they have convinced power holders in

¹ There is a large body of social science literature on dementia. Many authors have devoted themselves to making the person reappear behind dementia. Such authors problematize that too many people interpret everything that a person with dementia does in light of his or her diagnosis (inter alia and in particular Kitwood 1997). They challenge biomedical models of dementia (inter alia and in particular Lock 2016). Such works argue convincingly that people with dementia are not to be continually seen and treated as patients. I do not consider that referring to someone who is living with dementia as a patient is a form of insensitive and demeaning language but rather one option out of many. My thesis, as it will unfold, is about plurality in representational practices, about the value of multi-dimensional representations. Choosing technical terms is a practice of linguistic representation and I understand variation in labeling people / patients / citizens who are living with dementia as a means of pluralizing representational practices.

many countries that they are *in the know* about the pressing needs of patients living with dementia. However, rather than engaging directly with patients living with dementia they learn about the apparent (!) needs of patients with dementia through the accounts of family members (Beard 2004, 2016; Ballenger 2006). Examples like these illustrate why it is important to examine critically any attempt of political patient representation, “elaborating the character of the representative claims [and] paying detailed attention to the conditions under which claims are made, received, and assessed” (Saward 2010). Scholarship needs explore the ways in which, by whom and how patients become represented politically and the kinds of patient constituencies that are created in the process. What is more, it needs to reveal mechanisms that help us to recognize patient acceptance and identification with a representative claim. Such a critical examination, then, might equip us to better judge whom to listen to regarding patients’ political interests – and whom not to.

Research question and contribution of the thesis

My thesis explores representative claims about patients from a theoretical and comparative political perspective. The central research question of my thesis is:

How is political patient representation being performed, and what effects do the representative efforts of patient organizations and parliamentarians have in terms on patients’ political presence in the field of public health policy?

I am interested in uncovering how, to what extent, and in what contexts patients are represented in the political arena. I focus on POs and parliamentarians, as these two actors can be conceived of as distinct (and possibly competing) actors performing political patient representation, and I suggest that contrasting their representation work helps to gain a better view of the potentially multifaceted aspects of representative claims about patients. My dissertation aims to explore the grounds upon which POs and parliamentarians base their claims about patients, and to show how and to whom they try to make their representative efforts plausible. Furthermore, it seeks to shed light onto the expectations and requirements that political patient representatives need to fulfill in order to get their claims accepted. I

intend to look at the processes that result in the creation of a political presence for patients. This includes paying close attention to mechanisms that are expected to heighten the democratic quality of political patient representation by granting patients control over how and by whom they are rendered politically visible and audible. Taken together, my thesis aims to gain a fuller sense of how patient constituencies are constructed and of what form political patient representation takes.

The thesis marks, to the best of my knowledge, the first attempt to systematically relate the state-of-the-art in political representation theory to Political Patient Studies. It seeks to make a particular contribution by looking into the politics of patient representation through the theoretical lens of representative claims theory. Regarding the practice of voicing the wants and needs of patients in processes of political decision making, it is the objective of my dissertation to critically reflect upon whom to listen to, and when and why to do so.

Empirically, my dissertation makes use of a combination of different qualitative research methods of data accessing and analysis to answer my research question. The methods used belong to the set of non-positivist qualitative methodology.

[Within political science such methods] have increasingly been termed 'interpretive' methods because of their intentional, conscious grounding in or family resemblance to the ontological and epistemological presuppositions of the Continental interpretive philosophies of phenomenology and hermeneutics (and some critical theory) and their American counterparts of symbolic interactionism, ethnomethodology, and pragmatism, among others. (Yanow 2003)

Interpretive policy-analytic approaches have proven to be of scholarly value because they help to gain a fuller and more in-depth understanding of phenomena (Schwartz-Shea and Yanow 2012; Law 2007). My findings will supplement knowledge of practices of making patients matter to politics and of the wider field of political representation. I carefully selected settings and cases that promised significant and critical insights into the current political patient representation situation and chose methods of data accessing and analysis accordingly. None of my studies align to an epistemological understanding that presupposes the possibility of generalized conclusions drawn from empirical findings (Thomas 2011).

This means that my research on POs and parliamentarians does not claim to offer universally valid insights about POs and parliamentarians. The findings are not to be transferred to other settings; they do not aim to make conclusions about political patient representation *in general*. The findings rather aim to become a part of the trajectory of Political Patient Studies by offering “points of contrast, comparison or reference for other sites and situations” (Mol 2008) and by shifting conceptions about practices of making patients matter to politics.

Findings aim to inspire scholars on the topic of representation. Empirical studies on non-elective representation –as performed by POs, for example – continue to be few and far between (Kuyper 2016; Van de Bovenkamp and Vollaard 2017; Wolff 2013; Chowdhury 2019; Flöthe 2020). There is also little insight into how representative claims that parliamentarians make beyond / despite / independent of / in addition to their elective mandate unfold in practice (Mansbridge 2003; Severs et al. 2013). With my empirical findings and the related discussions, I therefore seek to inspire political science representation theory to further develop theorizations and to contribute to the development of research tools for exploring the empirical actualities of representative claims (Wilde 2013, 2019; Heinisch and Werner 2019; Guasti and Geissel 2019).

My thesis seeks to increase the interdisciplinary relevance of political science in the field of health. Within political science there is a debate going on about the discipline’s relevance. That debate revolves around the question of whether political science needs to increase its relevance for practitioners and citizens (Senn and Eder 2018; Byman and Kroenig 2016; Schütt-Wetschky 1990). By focusing on this question, the debate overlooks the academic relevance of political science *beyond* its disciplinary boundary. There is an overall scant attention of political science in the broader field of social science health research.

(P)olitical science’s arrival to the realm of health has been slow. By comparison, health-specific fields have long been active in every other social science discipline, e.g., medical anthropology, the history of medicine, health economics, medical sociology, etc. (Carpenter 2012)

Political scientists have been criticized for by and large approaching issues of health policy for the benefit of political science, i.e. for using them to test and further develop political science theories (Noweski and Engelmann 2006; Gagnon et al. 2017). In stark contrast, other social science scholars have been applauded for significantly contributing to a better understanding of health politics and policy making by bringing their discipline's accomplishments to the interdisciplinary social science research field on health (Leeuw et al. 2014). My thesis does not use the issue of the political presence of patients as a test example for representation theory. I rather consider my thesis as a case of boundary work. Combining interdisciplinary literature with political science theories, I hope that my dissertation will attract the attention of various social science disciplines. Scholars of Science and Technology Studies (such as Epstein 1995, 2008b), bioethicists (such as Schicktanz 2015; Schicktanz et al. 2018), medical sociologists (such as Rojatz 2016), and Patient Science academics (Van de Bovenkamp 2010) wonder about why and how to make patients matter to politics. My dissertation seeks to help fill the political science gap in Political Patient Studies, to highlight the relevance of political science for the interdisciplinary endeavor of a better understanding of practices of channeling patient preferences to political decision making processes, and to attract more political scientists to contribute to the broader field of social science health research (Mattila et al. 2019).

Outline of the thesis

For my paper-based thesis, I conducted four studies and prepared four manuscripts. Manuscripts will be introduced in each chapter (chapters 2-5). The last chapter (chapter 6) is an overall discussion of my thesis.

Chapter 2 addresses legal regulations on political patient representation work performed by POs. Based on a framework analysis of Austrian and German laws, the study sheds light on the requirements that POs need to establish in order to be officially accepted as patient representatives. The study focuses on Austria and Germany; two countries in which POs have recently been observed increasing their engagement in political activism (Etgeton 2009; Forster 2015, 2016; Kofahl et al. 2011). The findings of

this study are then compared with previous insights into legal requirements for Dutch POs. That is because, in contrast to Austria and Germany, in the Netherlands the involvement of POs in policy decision making is no recent phenomenon, and the Dutch healthcare system has gained much experience with the political activism of POs (Van de Bovenkamp and Trappenburg 2011). Exposing whether legislators share the same ideas with political theory on what makes a non-elective claim-maker (such as a PO) worthy of recognition as representative, the chapter contributes to the empirical representation literature that seeks to come to better understanding of the effect of real-life mechanisms of acceptance of representatives by an audience other than the constituency (Guasti and Geissel 2019).

Chapter 3 explores the representation work of Austrian, German, and Dutch POs, looking into how political patient representation by POs unfolds in practice and whether their efforts count as acts of democratic patient representation. Democratic patient representation requires the acceptance of patients. The relationship between the claim-maker and the constituency is considered crucial for democratic representation (Urbinati and Warren 2008; Saward 2009). Concerning authorization and accountability, various mechanisms can help patients to (re-)gain control over their choice of representative and provide them with opportunities to correct and modify their political presence. Theorists, for instance, argue that claims-making organizations such as POs can be considered as an authorized representative when constituents join the organization as members; and they are held accountable through the possibility for constituents to terminate their membership (Montanaro 2012, 2019). In theory, mechanisms of authorization and accountability are expected to have the potential to turn representative efforts into democratic representation. The present study aims at contributing to answering the question whether mechanisms work out in practice as suggested by theory. The study focuses on POs on rare diseases. Among different disease-specific POs, the literature suggests that POs on rare diseases are persistent and experienced when it comes to political activism (Huyard 2009a, 2009b). Results from a content analysis of documents published by 33 POs as well as from 24 semi-structured interviews offer insights into the practical challenges that POs encounter when seeking to

act according to criteria required by legislation (as analyzed in the first study) and criteria on democratic representation suggested by political theory (as explained above). The chapter reflects upon whether POs should only be listened to if they perform political patient representation in a democratic manner – as emphasized by important threads of representation theory (Montanaro 2012, 2019; Urbinati and Warren 2008).

Chapter 4 turns towards parliamentary patient representation. An interpretive analysis of parliamentary documents (such as plenary protocols) displays the representative claims that German parliamentarians make about palliative patients when debating a bill on palliative and hospice care — a debate that parliamentarians themselves described as a parliamentary moment of glory. The chapter is of interests for an interdisciplinary readership. It is of relevance, for instance, for bioethicists who problematize that political debates about end-of-life policies continue to pay too little attention to the wants and needs of palliative patients (Jox 2017). As explained earlier, studying practices of giving voice to patients in healthcare policy making is high on the research agenda. The chapter aligns to that agenda, adding empirical insight into instances of parliamentary patient representation to the Political Patient Studies literature that so far has focused on exploring how patient organizations, patient boards and individual patients try to make patients matter to politics. Uncovering how parliamentarians perform political patient representation, the study seeks to inspire representation theory and to increase our sensitivity towards representative claims that parliamentarians make beyond / despite / independent of / in addition to their elective mandate (Mansbridge 2003; Severs et al. 2013).

Chapter 5 presents findings from a thematic analysis of 56 parliamentary documents that show what kind of political presence German parliamentarians create for patients living with dementia. Political dementia research spans many disciplines (Nedlund and Nordh 2015; Nedlund and Taghizadeh Larsson 2016; Beard 2004, 2016; Ballenger 2006; Gerhards et al. 2017; Schicktanz et al. 2018; Wu et al. 2014). Yet again, there is little effort coming from political science (Behuniak 2010) – which is problematized by political scientists themselves (Sonnicksen 2016a, 2016b). Patients living with dementia qualify as an interesting case for assessing attempts of political patient representation because of the obvious

diversity among the members of a dementia constituency in terms of cognitive capacity to understand and accept or reject representative claims about them. Cognitive impairment accompanies most dementia trajectories and while many persons at an early stage do possess the cognitive capacity to accept or reject a representative claim that targets them as constituents, most persons at an advanced stage of dementia don't (Wallesch et al. 2017). The representation literature too often applies a simplistic differentiation between representative claims that target a constituency capable of acceptance and those claims that target an incapable constituency – such as animals or the environment (Boström et al. 2017; Essen and Allen 2017). It is, however, more likely that many (if not most?) constituencies consist of members capable of acceptance (and rejection) as well as of members incapable of acting acceptance (and rejection) – as foregrounded by scholars exploring representative claims about children (Holzscheiter 2016; Whiteside 2019). A study about representative claims about patients living with dementia thus substantiates the argument to give up the either-or understanding of constituencies and potentially encourages political theory as well as empirical works on the matter to pay more attention to the diversity among the members of a proclaimed constituency in terms of acceptance capacity.

Chapter 6 brings together the findings of my four studies and reflects upon their scholarly value in terms of existing scholarship on representation. It reflects upon the thesis' contribution to answering the question as to whether and how patients matter to politics. It discusses the importance of patients' political presence and the consequences that follow enactments of political patient representation in terms of public health policy. Moreover, it problematizes the limitations of my work and makes suggestions for future research.

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On legislating political patient representation

Increasingly, governments are inviting patient organizations (POs) to participate in healthcare policy decision-making (Löfgren, de Leeuw, and Leahy 2011). This happens especially in countries with healthcare systems classified as “social insurance systems,” such as the Netherlands, Austria, and Germany (Saltman, Busse, and Figueras 2004; Van de Bovenkamp, Trappenburg, and Grit 2010; Van de Bovenkamp and Trappenburg 2011; Forster 2016). There are multiple reasons for governments to involve POs. Besides normative arguments emphasizing democratic decision-making and the increased legitimacy of such decisions, there are also functional reasons (Charles and DeMaio 1993; Van de Bovenkamp, Trappenburg, and Grit 2010). The integration of experiential knowledge of patients in healthcare policy decision-making is expected to lead to better—more patient-oriented—decisions (Van de Bovenkamp, Trappenburg, and Grit 2010) and contributes to a plurality of perspectives in policy decision-making (Schick Tanz 2015).

Studies have shown that governments intervene quite substantially in the work of POs. In order to get funded or be invited to decision-making processes, POs have to correspond to governmental expectations (Van de Bovenkamp and Trappenburg 2011; Baggott and Jones 2014). Research from the Netherlands revealed that the Dutch government has created its own friendly opposition by steering patient organizations’ structural arrangements, their activities, and their ideology (Van de Bovenkamp and Trappenburg 2011; Waardenburg and Van de Bovenkamp 2014). Other studies have discussed the danger of POs getting invited by governments to solely increase the legitimacy of governmental decisions and advance government’s interests (Rojatz 2016; Souliotis et al. 2017). Findings like these give reason to conclude that governmental intervention might compromise the authenticity of POs, which calls into question their credibility to act as representatives based on the experiences and the will of their members.

This paper takes a closer look at the circumstances under which governments invite POs to take part in policy decision-making. According to representative claims theory, representation is a process that begins with a claim, with X claiming to represent Y. Representation then only comes into being in case such a representative claim is being accepted by the actor to whom the claim is addressed (Saward 2010). From this point of view, patient representation comes into being when governments accept a PO as patient representative. However, little is known about the criteria that predetermine governmental acceptance of the representative role of POs (Baggott and Forster 2008; Keizer and Bless 2010).

Austria and Germany make good cases to study the criteria for governmental acceptance of POs: In both countries, patients organize themselves mainly in the form of mutual self-help (aka self-help or mutual aid groups). In these groups, those affected and/or their relatives/carers meet regularly to share their daily experiences dealing with their condition. Moreover, they support each other in coping with and managing their situation through ongoing dialogue (Trojan and Kofahl 2011). Over time, these groups can join together to form self-help organizations (SHOs) which are characterized by activities such as raising public awareness about their conditions and advocacy in healthcare policy (Löfgren 2006). Given this mutual exchange of experiences among those affected within SHOs, they are considered to be “key mediating structures” between patients and the healthcare system (Branckaerts and Richardson 1988; Chaudhary, Avis, and Munn-Giddings 2013). Thus, SHOs are not only the most important form of patient organization in Austria and Germany but are also promising patient representatives.

With our study, we aim to contribute to the discussion on governmental steering of patient representation and on how we should value such intervention. It does so by answering the following research question: With what criteria do SHOs have to comply in order to be accepted as patient representatives on the national level of healthcare policy decision-making in Austria and Germany? To answer this question, we used national legislation as an indicator of the conditions under which patient representatives are accepted by Austrian and German governments.

The article proceeds as follows. First, we explain the methods used for our study. Next, we go into the results of our analysis showing the criteria defined by Austrian and German governments for patient representation. In the last section of our paper, we ask how we should value these criteria and conclude that government interference in SHOs can contribute to making patient representation more democratic.

Methods

To answer our research question, we analysed legislative texts. We were interested in the governments' criteria for SHOs representing patient interests according to national law in Austria and Germany. We chose Austria and Germany for our exploratory study because both healthcare systems can be characterized as "social insurance healthcare systems" and increasingly recognize SHOs as patient representatives. However, they differ in their regulation for patient representation by SHOs. Whereas Germany has quite elaborate regulations for patient organizations representing patient interests, Austria does not (Forster 2015).

To identify relevant legislative texts, we conducted a keyword search in the national legal information systems of Austria and Germany in May 2017. Our search terms are illustrated in Table 1.

Table 1 Search strategy

Search term	Translation	Number of documents Austria	Number of documents Germany
Patientengruppen	patient groups	3	13
Patientenorganisationen	patient organizations	3	3
Selbsthilfegruppen	self-help groups	8	9
Selbsthilfeorganisationen	self-help organizations	1	1
Patientenvertreter	patient representative	3	0
Patientenvertretung	patient representative bodies	2	0
Patientenvertretungen	patient advocacy groups	16	0
Patientenbeteiligung	patient participation	0	1
Maßgebliche Organisationen	[technical term to describe relevant organizations—in the context of patient representation]	0	2

Our search strategy led us to national legislation containing paragraphs with our keywords. We excluded legislative texts not referring to patient representation. In Austria, we also identified texts on patient representation referring to patient representative bodies (“Patientenvertretung”) without defining which organizations are meant. We excluded these from our analysis because there was no certainty about whom—SHOs or other actors—the passage addressed.

We developed an extraction scheme to extract the same content from all texts (when applicable). We extracted information on which types of organizations are considered eligible to represent patient interests (e.g. a kind of civil society organization), criteria for organizations representing patients (e.g. ascribed functions, organizational characteristics to be fulfilled, ideology), and the consequences for SHOs if they do (not) fulfil the criteria defined in the legislative texts. Additional information on the country, the name of the legislative text, and the date of extraction was collected.

Data were analysed using framework analysis (Ritchie, Spencer, and O’Connor 2003). After familiarization with the extracted information, data were paraphrased in our own words. After applying

this to all extracts, we used an excel sheet to compare the criteria for organizations representing patients in Austria and Germany. It also facilitated our discussion on similarities and differences in patient representation regulations between the two countries.

In Austria and in Germany, governments accept SHOs that are organized as associations. In both countries, there are general regulations for associations (A3, G5). Although criteria for SHOs as patient representatives don't refer explicitly (e.g. by cross-referencing) to regulations for associations, we considered legislation on associations as implicit regulation of patient representation. This is because SHOs organized as associations must fulfil these criteria in addition to the specific regulations on patient representation. Therefore, we included legislative texts on associations (A3, G5) defining the requirements for them. We also included legislative texts defining SHOs (G6) (Mayring 2010). An overview of all texts included is presented in table 2.

Table 2 Overview of included legislative texts

Document	Country	Code
Legislation on organizations identified by keyword search		
Vereinbarung zur Sicherstellung der Patientenrechte: Patientencharta 2006 (Patientencharta Wien)* <i>[Agreement to safeguard patients' rights: Patient Charter 2006]</i>	AT	A1
Bundesgesetz, mit dem ein Bundesgesetz zur partnerschaftlichen Zielsteuerung-Gesundheit (Gesundheits-Zielsteuerungsgesetz—G-ZG) erlassen wird 2017 <i>[Federal Act, with which a federal law on partnership-based target-oriented health management is to be enacted]</i>	AT	A2
Verordnung zur Beteiligung von Patientinnen und Patienten in der Gesetzlichen Krankenversicherung Patientenbeteiligungsverordnung 2003 <i>[Patient Participation Regulation 2003]</i>	G	G1
Verordnung zur Beteiligung der auf Bundesebene maßgeblichen Organisationen für die Wahrnehmung der Interessen und der Selbsthilfe der pflegebedürftigen und behinderten Menschen sowie der pflegenden Angehörigen im Bereich der Begutachtung und Qualitätssicherung der Sozialen Pflegeversicherung 2013 <i>[regulation on the involvement of organizations at federal level that are relevant for the protection of the interests and self-help of people in need of care and disabled persons as well as of caregiving relatives in the field of assessment and quality assurance of the Social Nursing Care Insurance 2013]</i>	G	G2
Sozialgesetzbuch: Fünftes Buch 1988 <i>[Social Code: Fifth Book 1988]</i>	G	G3
Sozialgesetzbuch: Neuntes Buch 2001 <i>[Social Code: Ninth Book 2001]</i>	G	G4
Additional legal texts		
Bundesgesetz über Vereine 2002 <i>[Federal Act on Associations 2002]</i>	AT	A3
Bürgerliches Gesetzbuch 1896 <i>[Civil Code 1896]</i>	G	G5
Sozialgesetzbuch: Elftes Buch 1994 <i>[Social Code: Eleventh Book 1994]</i>	G	G6

AT = Austria; G = Germany; * The text is drawn up for each Austrian federal text with similar content. Instead of naming all nine identical documents, we chose to cite the Vienna version as an example.

Findings

In the following, we present the results of our analysis. We start by providing an overview of regulations that explicitly address SHOs as patient representatives. Next, we show that, in addition to those explicit criteria, there are also implicit criteria in both countries.

Explicit Criteria for SHOs as Patient Representatives in Austria and Germany

In Austria, there are few criteria for the representative role of SHOs. Legislation does nominate self-help umbrella associations as patient representatives and offers them an institutionalized position to represent patients: “Umbrella associations of patient self-help groups shall be given the opportunity to be consulted on draft regulations and patient-relevant laws” (Art 30 A1, translation DR). Austrian self-help umbrella associations may further delegate a joint representative to the major national advisory body on healthcare (A2). Our findings suggest that Austrian regulations emphasize the role of self-help umbrella associations in representing the interests of patients. However, regulations do not provide specific criteria that self-help umbrella associations must fulfil with respect to patient representation.

Next to offering umbrella associations of patient self-help groups an institutionalized position in patient representation, regulations also mention self-help groups, which attend to patient interests (A1). These self-help groups are mentioned in relation to public bodies established to support and represent patients. These public bodies, also known as patient advocates, are considered independent and are not bound by directives or instructions. They are expected to support individual patients in conflicts with healthcare facilities as well as represent collective patient interests. They can do the latter by, for instance, providing official statements in decision-making processes that are relevant for patients (A1). These public bodies “have to seek cooperation with self-help groups that safeguard patient interests” (Art 29 Par. 2 A1, translation JF). Details or criteria for this cooperation are not provided (A1).

Although legislation provides an institutionalized position to SHOs as patient representatives, we found hardly any criteria that SHOs must meet in order to be accepted as patient representatives. Therefore, we argue that legislation in this respect remains rather vague in Austria.

Compared to the Austrian regulation, German legislation is more extensive. Core characteristics of self-help groups and SHOs are defined by law.

Self-help groups are voluntary, neutral, independent, and non-profit associations of persons affected personally or their relatives pursuing the goal of improving the life circumstances of those dependent on care and of their relatives and comparable persons close to them, through personal mutual support as well as through the aid of offers by volunteers and other persons prepared to commit themselves to civic engagement.

Self-help organizations are associations of self-help groups. (§ 45d G6, translation DR)

In Germany, legislation allows for patient representation in, amongst other bodies, the Federal Joint Committee, the main decision-making body in healthcare (G3). Legislation provides criteria, which must be fulfilled in order to be accepted as a patient representative. SHOs that want to be accepted as patient representatives within this and other bodies must fulfil the following criteria:

1. Promote the interests of patients or of self-help-in accordance with their statutes—ideally not temporarily;
2. Comply with democratic principles regarding their internal structure;
3. Represent the interests of patients or the self-help of chronically ill and disabled people at the national level according to their constituency;
4. Exist for at least three years at the time of recognition and have been active nationwide during this period within the meaning of item 1;
5. Provide the guarantee for proper fulfilment of tasks. The nature and extent of the previous activity, the membership, and the performance should be taken into account;
6. Demonstrate, through disclosure of their financing, that they function neutrally and independently; and
7. Pursue charitable purposes. (§ 1 G1, translation DR)

These criteria are defined not merely for SHOs, but for all organizations claiming to represent the interests of patients and mutual self-help in order to be accepted as representatives (G1, G2). We found that German legislation holds all organizations representing patients to the same standards. When the above-mentioned criteria are fulfilled, organizations representing patients are granted administrative,

factual, and financial support (G3). If there are questions concerning the fulfilment of these criteria, the Federal Ministry of Health is requested to review those organizations representing patients. Subsequently, it decides on a rejection or a revocation of acceptance of the organizations as patient representative (G1, G2).

Implicit Criteria for SHOs as Patient Representatives in Austria and Germany

We found that, in both countries, governments consider a SHO a legitimate representative when the organization has a statute and is organized as an association (A1, G1, G2). There is legislation in place that defines what is to be regulated in these statutes: associations are required to have certain internal structures and a membership structure in place (A3, G5). Statutes must determine who can become a member of the association and what goals and objectives the association pursues. Statutes must also regulate mechanisms for appointing the board and any other executive body of the association—via elections, for instance. The exact content of the statutes is defined by the associations' members. Members have to agree on the competence and period of office for the board and any other bodies. Moreover, they have to agree on the way in which and how often the board (or any other executive body) must inform them about what has been done on their behalf (A3, G5). Because members of associations decide upon the statutes, sovereignty is granted by assigning the decision-making power to them. Consequently, statutes can only be altered by members.

Discussion

We analysed national legislation on criteria to be fulfilled by SHOs in order to be accepted as patient representatives in Austria and Germany. In line with previous research (Forster 2015), we found different degrees of regulation (very little in Austria, more in Germany). Moreover, we learnt that governments in both countries formulate *explicit* criteria on patient representation as well as *implicit* ones for SHOs that are organized as associations. In the following we discuss how we should value the criteria for accepting the claim of SHOs to be patient representatives.

As shown in the introduction, research so far has come to a rather critical assessment of governments exerting influence on POs, arguing that governmental intervention might compromise the authenticity of SHOs and therefore their credibility to act as representatives based on the will of their members (Van de Bovenkamp and Trappenburg 2011; Waardenburg and Van de Bovenkamp 2014). However, a lack of regulation can also cause problems. As our methods section shows, we had to exclude some Austrian legislative texts on patient representation because it was unclear to which patient representatives they referred—SHOs or not. Austrian self-help representatives themselves have addressed the lack of clarity about which organizations can be accepted by governments as patient representatives: “The opaque definition of self-help groups and of who is legitimized to represent patient interests allows for an uncontrolled growth of both” (APA 2009, translation DR). While German legislation establishes clarity on the binding nature of patient representation, the Austrian legislation leaves this rather open. The comparison of Austrian and German legislation shows that, thanks to defined criteria on patient representation, legislation can establish clarity about which organizations can be accepted as patient representatives by governments. Furthermore, legislation might prevent governments from randomly accepting or rejecting actors claiming to represent patients.

Besides clarity about governmental acceptance of patient representatives, patient representation might also benefit from regulation for democratic reasons. In the following, we discuss in turn responsiveness and independence as two theoretically informed features that are established by legislation and that contribute to making patient representation more democratic.

In line with political theorists working on representation, we argue that democratic representation requires *responsiveness*: the continuous interaction between the representative and the represented (Urbinati and Warren 2008; Montanaro 2012). Responsiveness is often conceptualized in terms of authorization and accountability (Pitkin 1967; Urbinati and Warren 2008; Montanaro 2012; Van de Bovenkamp and Vollaard 2017). The concept of authorization addresses the question of how a representative gets appointed or directed as such. Accountability is about the “relationship between an actor and a forum, in which the actor has an obligation to explain and to justify his or her conduct,

the forum can pose questions and pass judgement, and the actor may face consequences”(Bovens 2007, 447). Legislation in both countries arranges for SHOs to offer membership to those they claim to represent and to let the members elect the governing boards of SHOs. Moreover, they have to agree on the way in which and how often the board (or any other executive body) must inform them about what has been done on their behalf (A3, G5). These means are mechanisms for authorization and accountability; through casting votes for a board member authorization is established and through the re-electing or voting out of a board member accountability is. Similarly, membership can be seen as a mechanism for both authorization and accountability. Constituents authorize the claims-making organization through becoming a member and hold the organization to account through exit or anticipation of exit (Montanaro 2012). We therefore argue that by linking criteria for SHOs to those for associations, legislation aimed at establishing responsiveness can foster SHOs to perform representation in a democratic manner.

Independence is a feature that, according to representative claims theory, adds credibility to the claims representatives make (Saward 2010). Literature on SHOs often addresses the financial dimension of independence, discussing the potential dependency of SHOs on sponsors, such as the pharmaceutical industry, medical device manufacturers, and governments (O’Donovan 2007; Van de Bovenkamp and Trappenburg 2011; Vitry and Löfgren 2011; Colombo et al. 2012; Schulz-Nieswandt and Langenhorst 2015). Funding by such sponsors—especially if POs depend on one or only a few big funders—make SHOs susceptible to external influence and might be accompanied by expectations and criteria of the funders. Disclosing the finances of SHOs—as required by German legislation—reveals possible conflicts of interests and potential steering of these organizations. Therefore, also in this regard regulation can help strengthen the credibility of SHOs as patient representatives.

Our research contributes to a more comprehensive discussion and appraisal of governmental influence of SHOs. However, the study has some limitations. Because of its explorative nature, it only focused on the national legislation of two countries. We suggest exploring additional country cases for

future research. We focused on SHOs, but given that there are many actors claiming to represent patients (see Van de Bovenkamp and Vollaard in this issue), it would also be interesting to explore what criteria actors other than SHOs must fulfil to have their representative claims accepted by governments. Moreover, we are aware that legislative texts are not the only source for regulating patient representation (Van de Bovenkamp and Trappenburg 2011) and that other documents, such as procedural rules of healthcare decision bodies, refine legislative regulations.

Conclusion

In this study we contribute to the existing literature by showing that governmental intervention in patient representation should not only be seen as negative per se as previous research indicates. Depending on the criteria used, government influence can play a positive role in ensuring democratic patient representation. First, legislation can ensure clarity about which organizations governments accept as patient representatives. This is important because of strengthening transparency in patient representation and avoiding governmental arbitrariness in accepting patient representatives. Legislation therefore might help to secure that POs/SHOs get accepted by governments as patient representatives even when being critical of the government. Second, our results show that legislative criteria on patient representation potentially strengthen democratic patient representation by promoting both responsiveness and independence. Future research will need to take a look at how SHOs put these criteria into practice. Furthermore, we encourage studies that explore whether governmental criteria match the acceptance criteria of patients.

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The representative efforts of patient organizations

Patient organizations (POs) engage in health policy making in various countries. They lobby politicians, organize protests and petitions, publish opinion statements on proposed legislation, engage with mass media and—more and more often—get invited to participate in different settings of policy decision making. They participate in public hearing processes as well as in advisory and decision-making boards (sometimes with and sometimes without voting rights). There are many examples of policy topics that POs have joined the debate on—such as eHealth, telehealth, patient safety, health literacy, education for future healthcare professionals, access to healthcare provision in general and specific drugs, medical devices, and methods of alternative medicine in particular (Gerhards et al. 2017; Rojatz and Forster 2017; Epstein 1995, 2008; Keizer 2012; Baggott and Forster 2008; Forster 2015, 2016; Kamphuis et al. 2012; Keller and Packel 2014; Löfgren et al. 2011; Van de Bovenkamp et al. 2010; Van de Bovenkamp and Zuiderent-Jerak 2015).

Literature has discussed the engagement of POs in health policy making critically, problematizing, for instance, the financial dependence of many POs on sponsors such as the pharmaceutical industry, medical device manufacturers, and the government (O'Donovan 2007; Vitry and Löfgren 2011; Van de Bovenkamp and Trappenburg 2011). A study on the Austrian case revealed that POs worry about their policy engagement because of difficulties such as work overload and lacking resources (Rojatz and Forster 2017). Engaging in health policy making is not the sole activity that POs carry out. In Austria—as in many other countries—self-help organizations constitute the majority of POs. In addition to raising public awareness for the disease(s) that the organization covers, their main aim is to promote peer support of patients (and their family caregivers) (Forster et al. 2011). To this effect, they support patients (and family caregivers) to mutually support each other in coping with their diseases.

At the same time, literature has formulated many hopes connected to POs getting more engaged in health policy making. Along with arguing the inclusion of the experiential knowledge of patients will

result in an increased quality of decisions, scholars reason that the engagement of POs promotes democratizing health policy decision making (Van de Bovenkamp et al. 2010). However, the question as to what way their engagement contributes to democratizing health policymaking remains mostly unexplored in the literature.

To gain a better understanding of how POs contribute to shaping health policy decision making in a more democratic way, it is important to draw on the concept of representation (Castiglione and Pollak 2019). Representative claims theory describes representation as an “ongoing process of making and receiving, accepting and rejecting claims.” (Saward 2010) When engaging in health policy making, POs claim to represent the interests of patients (Rojatz and Forster 2017; Schicktanz et al. 2018). When being invited to participate in health policy making, they are accepted as patient representatives by those extending the invitation. Just because they perform patient representation, doing so does not necessarily mean that POs automatically contribute to democratizing health policy. Instead, work needs to be done on the representative relationship to turn representation into democratic representation (Van de Bovenkamp and Vollaard 2017; Urbinati and Warren 2008; Montanaro 2012; Näsström 2015).

For assessing the democratic value of a representative claim, it has become customary for scholars to look at the relationship representatives have with those they claim to represent. This relationship can be operationalized concerning authorization and accountability—meaning how representatives are directed or selected and how representatives can be held accountable for what they have done on behalf of their proclaimed constituency (Bovens 2007; Montanaro 2012; Pitkin 1967; Urbinati and Warren 2008). Elections are a well-known means of authorization (electing one’s own representatives) and accountability (re-electing or voting out one’s own representatives). Another formal means is membership. In organizations that offer membership, constituents (in our case patients) can become a member of the claims-making organization (in our case a PO). It is then that “membership will serve both authorization and accountability: through joining (authorization) and through exit or anticipation of exit (accountability).” (Montanaro 2012) There are also informal mechanisms that representatives can establish to strengthen the democratic value of their representative claim—such as allowing

deliberation in meetings or other contacts, accounting for one's conduct in the public debate and making action plans and goals publicly available (Montanaro 2012; Urbinati and Warren 2008; Van de Bovenkamp and Vollaard 2017).

Both formal and informal mechanisms for authorization and accountability do not promote democratic representation in case the group "empowered to authorize and demand accountability is different from the constituency whose interests the representative claim affect." (Montanaro 2012) Thus, it is essential to pay particular attention to how representatives align means for authorization and accountability to their proclaimed constituency.

This study presents how POs work on turning their representative efforts into democratic representation. The objective of our study is not to explore whether POs consider themselves as or aim to be considered democratic institutions. We also do not seek to explore what POs believe to be their contribution to democratizing health policy. Instead, our study departs from the assumption that POs contribute to the democratization of health policy when they perform democratic patient representation as conceptualized above. The paper proceeds in three steps. After describing our research design, we will present our results and show that POs have various means of authorization and accountability in place. Following that we discuss the difficulties POs are confronted with in their representation work and argue why more research needs to be done into the complex empirical reality of representation.

Research Design

Given the explorative nature of our research we prepared a qualitative study design. We studied POs covering rare diseases in Austria, Germany and the Netherlands, using document and interview data collected in 2016.

POs focusing on rare diseases make an excellent case to study the representation work by POs. The EU defines rare diseases as conditions that affect not more than 5 out of 10,000 people. Research has revealed that POs that cover rare diseases engage substantially in policy making (Douglas et al. 2015;

Henschke 2012; Huyard 2009a, 2009b; Rabeharisoa et al. 2014). Drawing on this insight, we chose to explore POs covering rare diseases due to richness in relevant information. Expecting points of contrast, we selected POs from Austria, Germany and the Netherlands. Despite different traditions of involving POs in health policy decision making, POs in all three countries have been witnessed to increasingly engage in political activism (Braunegger-Kallinger et al. 2009; Etgeton 2009; Forster 2015, 2016; Kamphuis et al. 2012; Keizer 2012; Rojatz and Forster 2017; Van de Bovenkamp et al. 2010). By excluding parental POs from our sample, we aimed at bounding complexity. To strengthen the power of our findings, we only added cases to our sample in which a rare disease was covered by a PO in all three countries. In total, we found 11 cases per country that matched our criteria—thus 33 POs. Except for one Dutch PO (a foundation), all selected POs were associations that offer memberships. All POs offered services like information provision and promoted patient peer support and were led by an elected and voluntary board and had no paid staff that perform representation. We cannot provide any further information on our selected POs other than the criteria mentioned above since we promised all selected POs anonymity. We did so in order to motivate our interview respondents to speak freely about the inner workings of their organizations.

Table 1

Selection of (interviewed) organizations per country

Country of Study	Number of POs
Austria	11 (8)
Germany	11 (10)
The Netherlands	11 (6)
All countries	33 (24)

Notes: Not all selected organizations agreed to be interviewed. The number of interviewed POs is given in the brackets ().

We used more than one method to gather our data. Applying methodological triangulation, we (i) collected online documents and (ii) conducted interviews.

First, we searched the websites of our selected POs for their statutes and constitutive documents as well as for all texts referring to their representation work that were published online in 2015. Online

documents included newsletters, magazines, brochures, leaflets, open letters, standpoints as well as shorter items announced in the news section of the website.

Second, we conducted semi-structured interviews with officials of the selected POs. Respondents were invited to explain which constituency their PO claims to represent and to elaborate on formal means of authorization and accountability—such as elections and membership. We questioned them about the interaction with their proclaimed constituency, about means to justify their conduct to the represented and about opportunities for the constituency to pose questions and pass judgement on the organization’s conduct. Respondents were asked to give examples to illustrate their statements. The interviews lasted between 40 minutes and one and a half hours. The interviews with Austrian and German respondents were held in German, while the interviews with Dutch respondents were held in English. We recorded and transcribed all interviews.

For the thematic analysis (Flick 2017) of our data we composed an analytical scheme of themes: (i) the representative claims of POs and their proclaimed constituency; (ii) formal means of authorization and accountability described by representation theory; (iii) informal means of authorization and accountability. For analyzing our data, we paid particular attention to how POs align mechanisms for authorization and accountability to their proclaimed constituency.

Representation work of patient organizations in practice

In the following section, we describe the formal and informal mechanisms of authorization and accountability that POs have in place. First, however, we show whom POs claim to represent, which is vital for understanding how their established mechanisms for authorization and accountability contribute to making their representative work democratic.

Patient organizations and their proclaimed constituency

Patient organizations differ regarding whom they claim to represent. We found POs that claim to represent patients only. Others add caring relatives of patients to their constituency.

We represent the interests of people suffering from [name of the disease] and their families and caring friends.

(Statute, German PO)

Moreover, some POs claim to represent only members of their association and other POs make broader representative claims which include non-member patients (and non-member family caregivers).

We view ourselves to be the representatives of all those affected in Austria. We are not so strict about whether somebody is a member or not. (Respondent, Austrian PO)

Patient organizations and formal means of authorization and accountability

POs have different mechanisms in place that are expected to serve both authorization and accountability. As explained in the introduction of this paper, political theorists argue that through offering membership organizations establish an authorization mechanism. Indeed, all selected POs were associations that offer membership except for one Dutch organization which was a foundation. However, we learned that many patients join a PO because they want access to specific services that the organization is offering—such as information and peer support—and that the decision to become a member often has little to do with showing support for the representation work of the PO. Thus, our findings suggest that membership as a means for authorization turns out unclear in case where organizations perform more tasks than mere representation.

There is a second difficulty with membership as an authorization mechanism that arises in practice. We found that not all POs aligned their regulations for membership with those they claim to represent. Not all POs that claimed to represent patients only, consequently offered membership exclusively to patients. Furthermore, we found POs in Austria and Germany that offered membership to any legal person.

Any legal person that is willing to support our goals can become a full member of the association. (Statute, German PO)

We learned that those POs which offer membership to any legal person also have non-constituents as members – such as healthcare professionals. In sum, this means that a large number of members is not necessarily a sign of broad constituent authorization.

Offering membership to non-constituents also bears consequences for the elections of the board. The board, which takes decisions on what to advocate for, gets elected by the members of the organizations. In general, elections serve as formal means of authorization and accountability and are seen as strengthening the democratic value of a representative claim by showing constituent consent and contributing to public control. Our findings, however, suggest that there are cases in which elections do not adequately serve their purpose. In an association, every full member has the right to vote for the board election, meaning that many POs also allow non-constituents to cast a vote. Offering voting rights to non-constituents is problematic for democratic reasons. As explained before, it is crucial that the group of people that gets to elect the representative match the group of people that the representative claim is about and that only members of the constituency get to cast a vote.

We found two additional problems with elections as a mechanism for authorization and accountability. Many respondents reported difficulties in finding candidates who want a position on the board. Being a board member is an unpaid honorary position that comes with legal and other responsibilities and a substantial workload. Respondents guessed that because of these reasons people hesitate to run for board membership. As a consequence, many POs could not offer their members more than one candidate for each board position. The last problem related to this authorization and accountability avenue is about low voter turnout. Respondents reported that many members do not cast their votes because they take little interest in the board.

They [the members] want their organization to fight for them, to stand up for them, to do things for their good.

But they don't care who is in the board. (Respondent, Dutch PO)

Patient organizations and informal means of authorization and accountability

The fact that there are difficulties attached to the formal mechanisms of authorization and accountability does not mean that there is no means of authorization and accountability in place. In addition to formal mechanisms, there are also many informal ones. We learned that POs trust different informal authorization and accountability avenues to strengthen the democratic basis of their representative claims.

For POs it is imperative to deliberate with their constituents for authorization purposes. Respondents argue that by learning what their constituents need and want, POs are directed in how to serve as representatives. POs learn from constituent stories about courses of diseases, successes as well as setbacks in treatments, medical and other problems related to being affected by the disease, deficiencies, and gaps in healthcare provision and so forth.

We have knowledge about what patients like and want and need. We are well informed in this regard.

(Respondent, German PO)

POs not only learn from stories their members share with them but also from stories they get through direct contact with non-member constituents.

A lot of patients come to us that are no members. They don't want to pay the membership fee. And they are afraid of getting outed as being sick and that everyone points their finger at them. In the end I probably talk to more non-members than members. (Respondent, Austrian PO)

Table 2
Interactive contact opportunities for patient organizations and their constituents

Contact opportunities regardless of local distance
<ul style="list-style-type: none"> • Telephone (n=33) • E-Mail (n=33) • Facebook • Online Fora with login
Face to face contact opportunities
<ul style="list-style-type: none"> • Members Appointments - such as the annual general assembly of the PO or meetings for networking and exchange (n=33) • Information and public events - such as a booth at a fair or protest marches • PO organized workshops and trainings • Discussion fora - such as standing working groups or round tables • Visits to individual constituents

As shown in Table 2, POs offer their constituents numerous contact opportunities. We learned that next to authorization these communication opportunities also serve accountability. Respondents explained that through interaction POs account for their representation work by reporting back to their constituency what has been done on behalf of them.

We are always explaining to the patients what is happening and why we are protesting against what kind of things. (Respondent, Dutch PO)

POs also prepare written information on their representation work—such as annual reports and reviews, newsletters, magazines, brochures, leaflets and short items announced in the news section of their website. These can also be seen as a mechanism of accountability. Moreover, we found POs that published concrete points of view and wrote down their policy positions for everyone to read. Examples of such publications are letters to politicians or other policy makers, in which POs demanded changes in health policy, raised concerns about certain developments or suggested solutions to pressing problems.

Despite different efforts to account for their representative actions, some POs partially fail to inform at least parts of their constituency. Not all POs that claim to also represent non-members put the same effort in informing these non-members. In many cases meetings are for members-only. Newsletters, magazines and mails are also often spread solely among members just as access to online-fora is granted only to constituents holding a membership.

Aiming to strengthen their efforts regarding authorization and accountability, POs not only wait but ask for constituent input. Respondents stressed the necessity to motivate constituents to share their stories (for authorization purposes) and to pose questions and pass judgement regarding the representative actions taken by the PO (for accountability purposes). Respondents further note that some constituents are harder to reach than others. For instance, to get the chance to talk to patients during the advanced stage of the disease, representatives of POs occasionally visit patients at home or at the hospital.

To conclude, we found POs in all three countries of study to work on turning their representative efforts into democratic representation. While we found both formal and informal mechanisms of authorization and accountability in place, our findings suggest that in practice not all means of authorization and accountability work out as hoped for in theory.

The challenge of performing patient representation democratically

In this section, we reflect on lessons learned by studying POs as a case of representation to gain insight into their contribution to democratizing health policy decision making. Drawing on concepts of authorization and accountability has proven to be insightful for studying the representation work of POs. We found that POs apply different formal and informal means of authorization and accountability to turn their representative efforts into democratic representation. POs attach more importance to informal means. They claim that it is vital to deliberate with their constituents for authorization and accountability purposes. Respondents argue that by learning what their constituents need and want they get directed as representatives. Regarding accountability, POs provide information on their representation work and offer their constituency various opportunities to pose questions and pass judgment on the organization's conduct.

Our findings point to further two difficulties that arise in (patient) representation practice. By discussing these difficulties in the following section, we aim to contribute to the scholarly literature on difficulties that POs face as patient representatives (Gerhards et al. 2017; Rojatz and Forster 2017; Schicktanz et al. 2018) as well as to literature on the empirical reality of representation (Van de Bovenkamp and Vollaard 2017; Kuyper 2016; Wolff 2013). We argue that POs differ regarding their democratic potential and that POs are confronted with challenges that—while not described by representation theory—arise in representation practice. POs differ regarding their democratic potential because they are dissimilar in alignment between the availability of authorization and accountability opportunities and their constituency. There are, for instance, POs that offer authorization and accountability opportunities to non-constituents (such as voting rights to healthcare professionals).

Regarding those POs that claim to represent also non-member patients (and non-member family caregivers), we found cases in which means of authorization and accountability are not open to all constituents alike. Often opportunities—such as electing the board of the PO, deliberation in member meetings, or participation in online fora—only come with membership. Non-member constituents are also put at a disadvantage by POs that do not provide the same information for members and non-members. In sum, it appears challenging to harmonize the means for authorization and accountability with the proclaimed constituency. For democratic reasons, it remains important to do so (Montanaro 2012).

POs are confronted with challenges that arise in representation practice. Many means of authorization and accountability do not work out in practice as described in theory (Disch 2015; Kuyper 2016; Montanaro 2012; Näsström 2015; Saward 2009, 2010; Van de Bovenkamp and Vollaard 2017; Wolff 2013). We raise two concerns. First, our study shows that patients as constituents do not seem to care much for the authorization and accountability opportunities POs offer. While especially formal means of authorization and accountability meet very little constituent response, POs also face difficulties getting constituents engaged with informal means. Other papers also describe that POs struggle to get their members interested in their policy work (Kofahl et al. 2010). Thus we suggest putting more future research efforts into exploring what makes patients and other represented care about being represented (Daoust and Blais 2018).

Second, our findings lead to questioning the practicality of means for authorization and accountability in multitasking organizations. Membership as an authorization opportunity is an excellent example to illustrate this concern. Patients join a PO for different reasons. Often, they are interested in offers of mutual self-help and search for support in overcoming daily problems related to their disease (Kofahl et al. 2010). In multitasking organizations that not only specialize in representation, the act of becoming a member cannot automatically be interpreted as an act of granting constituent authorization for the representative work of an organization. Moreover, patients also don't join a PO because of various reasons—such as fearing to be outed or not wanting contact to others at a more advanced stage

of their disease (Jones et al. 2004). Again, such reasons have nothing to do with the representative aspirations of a PO. Thus, by not becoming a member, patients do not necessarily withhold authorization and reject the representative claim of the PO. While we lack empirical understanding of what constituent absence means for a representative claim, at least representative claims theory argues that nonobjection can be considered as an act of constituent acceptance of a representative claim (Saward 2010). Drawing on findings of our and other studies (Van de Bovenkamp and Vollaard 2018), we therefore argue that more research needs to be done into the complexity of the empirical reality of representation in which representatives often perform not only representation but also other tasks.

Our study has limitations. Results show that the POs we studied differ in reaching their democratic potential but given the explorative nature of our research we are not able to explain for what reasons they do so. We found no evidence pointing to country-specific differences, yet our findings do not qualify for conclusions regarding disparities between POs from different countries. With our study we hope to shape ideas about the democratization of health policy by introducing a representation perspective on how POs may contribute to that goal. However, to this end observational data on how POs perform representation are needed to verify routines of democratic patient representation.

Conclusion

Our study departed from the assumption that POs contribute to the democratization of health policy when they perform democratic patient representation. We found their representation work to indeed matter to the democratic value of a PO. In addition to its scholarly value, we believe our findings have practical value: We recommend health policy makers to pay attention to how POs perform representation and to attach particular importance to informal means of authorization and accountability as described in this paper. Formal means of authorization and accountability – which in representation theory as well as by law are considered very valuable (Rojatz et al. 2018) – appear to be tricky to put into practice. POs attach more importance to informal means of authorization and

accountability. We, therefore, conclude that especially those mechanisms are essential to the contribution of POs for democratizing health policy decision making.

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On the parliamentary presence of patients

Studying practices of giving voice to patients in healthcare policy making is high on the research agenda. Patient organizations, patient boards and individual patients who participate in decision-making processes are the most researched examples of actors who are understood to voice the political preferences of patients based on their lived experience or their knowledge thereof (Baggott and Forster 2008; Conklin et al. 2015; Gauld 2010; Jones et al. 2004; Murphy 2005; Tritter 2011; Van de Bovenkamp et al. 2010; Epstein 1995; Rabeharisoa et al. 2014).

Only recently scholars have begun to explore practices of giving voice to patients through the lens of representation theory (Fischer and Van de Bovenkamp 2019; Gerhards et al. 2017). Scholarship has paid attention to the representative efforts of patient organizations (Van de Bovenkamp et al. 2010; Epstein 2008; Baggott and Forster 2008; Rojatz and Forster 2017; Souliotis et al. 2018; Rabeharisoa 2006; Jones et al. 2004), exploring how they work on turning their representative claims into democratic patient representation (Fischer and Van de Bovenkamp 2019; Gerhards et al. 2017; Van de Bovenkamp and Vollaard 2017), and how other actors – such as governments and the pharmaceutical industry – try to influence their representation work (Van de Bovenkamp and Trappenburg 2011; Rojatz et al. 2018; O'Donovan 2007). However, besides patient organizations also others perform political patient representation. Elected representatives, too, make representative claims about patients (Van de Bovenkamp and Vollaard 2017, 2018a, 2018b), yet little is known about instances of parliamentary patient representation (Pacheco and Fletcher 2015; Mattila et al. 2019).

Recent advances in representation theory (Disch 2015; Saward 2010) stress the importance of taking a broad view to representation by studying all actors who make representative claims about a certain group, arguing that this is important to gain a full sense “of the rich plurality of representative practices.”(Saward 2010) Representative claims theory further argues the importance of focusing on the dynamic processes within which claims-makers – such as parliamentarians – present themselves as

voicing relevant constituent interests. This includes observing how claims-makers construct the constituencies they claim to represent and what preferences and features they ascribe to members of their proclaimed constituencies. Also, it calls for studying how claims-makers justify, defend, and change the way they make their proclaimed constituency politically visible and on what basis their representative claims are accepted or rejected by others (Rehfeld 2005, 2018; Saward 2019; Disch 2019).

Drawing on representative claims theory, we present empirical insight into the under-researched area of representative claims about patients made by parliamentarians. We do so by answering the following research question: *What representative claims do German parliamentarians make about palliative patients and how do they debate their claims?* The process of drafting the German bill on palliative and hospice care makes an interesting setting for exploring elective patient representation – as will be reasoned in the next section of this paper.

Choice of setting, materials and methods of data interpretation

The drafting of the German bill on palliative and hospice care went smoothly. Across party boundaries, parliamentarians worked together on the bill that in the end introduced a better funding of hospice services and strengthened outpatient palliative care. This was for instance done through fostering interconnections between palliative care professionals and primary care physicians, and through increasing the possibilities for support of specialized healthcare professionals in the home setting. The bill further establishes the funding of professional consultation for residents of nursing homes who wish to document future decisions that direct healthcare professionals in situations when the resident is no longer able to make such decisions (Rixen et al. 2016; Melching 2017; Blank et al. 2018b). That the drafting of the German bill on palliative and hospice care went smoothly is surprising given the complicated and protracted debates that the German parliament held over other bills on end-of-life care, such as for instance the bill on advance healthcare directives (Borasio et al. 2011; Kaufmann 2015)

or the bill on assisted suicide that aimed at stopping right-to-die organizations in Germany and that was adopted in parallel to the bill on palliative and hospice care in 2015 (Nauck and Simon 2021).

Given its declared parliamentary glory status we chose to dive into the debate on palliative care to study the representative claims made and use it as an exploratory case to study representative claims about patients made by elected representatives. We conducted a qualitative analysis of parliamentary documents on the debate on the bill on palliative and hospice care. Documents were provided by the online archive of the German parliament – called the “Dokumentations- und Informationssystem für Parlamentarische Vorgänge”. The online archive collects documents that record the processes of debating German bills, bundles them per act and makes them publicly available. We included into our data set every document that was provided by the online archive in connection to the process of debating the German palliative and hospice care act. Next to written requests issued by members of parliament, the data set encompassed also transcripts of plenary sessions of both chambers of the German parliament – called “Bundestag” and “Bundesrat” respectively.

Table 1 Overview of documents collected and analyzed

Document	Code
Printed Matter 18/ 4563: Request by members of the parliamentary party <i>BÜNDNIS 90/DIE GRÜNEN</i> (Green political party)	D1
Plenary Protocol of the 934th session of the <i>Bundesrat</i>	D2
Printed Matter 18/5202: Request by members of the parliamentary party <i>DIE LINKE</i> (Democratic socialist political party)	D3
Plenary Protocol of the 111 th session of the <i>Bundestag</i>	D4
Plenary Protocol of the 115 th session of the <i>Bundestag</i>	D5
Protocol of the 50 th session of the <i>Ausschuss für Gesundheit</i> (Committee of Health)	D6
Plenary Protocol of the 113 th session of the <i>Bundestag</i>	D7
Plenary Protocol of the 939 th session of the <i>Bundesrat</i>	D8

To make sense of the research data, we performed an abductive analysis in an interpretive-informed manner (Tavory and Timmermans 2014; Schwartz-Shea and Yanow 2012). To begin with, the first author familiarized herself with the raw research data, reading and re-reading the documents. In a next step, the first author discussed the insights from her familiarization with the third author who himself had taken an overview over the data. Following the discussion and drawing on representative claims theory (Saward 2010; Disch 2015) as theoretical underpinning of the study, the first author developed an

analytical framework. The analytical framework was discussed between all authors until consensus was reached. Three categories shaped the analytical framework. The first category was designed to capture the type of representative claims made about palliative patients. The second category was designed to describe the construction of the constituency and focused on attributes and preferences that parliamentarians ascribed to their proclaimed constituency. The third category focused on how parliamentarians debated the representative claims made. The first author extracted text passages from the selected parliamentary documents and indexed extracts to the categories. She performed the interpretation by moving back and forth between theory and indexed extracts and in between categories. Co-authors acted as a corrective, challenging the interpretation in the light of the raw research data.

Results

Constructing the constituency of the palliative people

Throughout the process of discussing the bill on palliative and hospice care we found German parliamentarians across party boundaries to focus their representation work on a generic constituency. They conducted the debate on the palliative and hospice care act as a broader discussion on dying. Because of the connection to dying – which parliamentarians rendered as being fundamentally existential – the topic of palliative and hospice care became a subject that concerns everyone. This was central for creating the constituency of the *palliative people*.

Palliative and hospice care. We cannot avoid this topic. It concerns all of us, each and every one of us in this room. It is about our own finiteness. It is also about our own dying. (Translated quote, D4)

The constituency of the *palliative people* was beyond any distinction as parliamentarians established the constituency as encompassing ‘us’. ‘We’ were represented as palliative patients-in-waiting by raising the argument that in the future anyone can become a palliative patient, including parliamentarians themselves. Only rarely parliamentarians directed their representative efforts exclusively to patients

who are currently in the palliative phase. Instead, palliative patients were swallowed by the collective, abstract, inclusive 'we' that parliamentarians focused their representative attention on.

One time, another representative claim about 'us' was made. In this case 'we' were represented as future informal caregivers of palliative patients. To introduce the topic of palliative and hospice care, a parliamentarian argued that anyone is potentially affected by regulation on palliative and hospice care since in the future anyone could become a family member and hence an informal caregiver of a palliative patient.

This bill affects an area of our life that moves all of us as. Eventually it will happen to all of us. We know or sense how challenging it will be to care for and accompany a seriously ill or dying family member. (Translated quote, D4)

Next to the representative claim about 'us' as future informal caregivers of palliative patients, parliamentarians also made representative claims about various groups – such as voluntary hospice workers.

80,000 highly qualified voluntary hospice workers take care of those in need of palliative and hospice care. Those, who engage themselves in palliative care, must be supported – especially for the benefit and in the interest of the patients. That is why today we are discussing this bill. (Translated quote, D7)

However, as described earlier, for the most part parliamentarians directed their representation work towards the *palliative people* – respectively towards 'us' as palliative patients-in-waiting. Parliamentarians did pay attention to certain differences amongst 'us' by referring to a multitude of distinctive features. These features included age, cultural and religious backgrounds as well as types of diseases and conditions – such as cancer, dementia, and depression. Pointing out these differences was done to problematize unequal access to palliative care.

In nursing homes and in rural areas, palliative and hospice care is often not available. Access to palliative and hospice care remains difficult for people who are dependent on social security benefits, for residents of facilities for the disabled or homeless people and migrants. (Translated quote, D3)

The pointing out of the above-mentioned differences among the *palliative people* did not lead to identifying differences among the *palliative people* in terms of preferences though. Parliamentarians rather made distinctive features among the *palliative people* politically present to demand that the bill

needs to be prepared in a way that everyone has the same opportunities to reach the preferences that ‘we’ share. In the following, these projected preferences will be analyzed.

The palliative people: in want of self-determination and dying at home

Parliamentarians shared a portrayal of the *palliative people* as having ideas about their own death and dying and wishing to maintain control by planning in advance the last phase of their lives. Parliamentarians argued that self-determination in end-of-life (care) and dying is important for the *palliative people* as ‘we’ believe our dignity to depend on self-determination.

We associate dignity in old age with spending the last phase of our life self-determined and free of pain and hope to participate as much as possible. We don’t want to picture ourselves being dependent on others. Instead, we imagine our last days to happen surrounded by our relatives – not only well-fed and clean but accepted and respected. (Translated quote, D4)

We found no parliamentarian contesting this proclaimed preference of self-determination in end-of-life (care) and dying as the most important value, nor the adequacy of portraying death as a clean, well-ordered and communal process. Instead, parliamentarians repeatedly stressed the importance of drafting the bill in a way that enables palliative and hospice care to foster self-determination.

We need a palliative and hospice care that centers human dignity through respecting self-determination at the end of life.” (Translated quote, D4)

Interestingly, there was also a clear portrayal of how the *palliative people* would want to use their self-determination. Across party boundaries, parliamentarians supported the political preference of the *palliative people* to be cared for and die at home. Parliamentarians framed this preference towards outpatient care as a natural preference and a logic choice.

If someone would ask members of our group [of parliamentarians] to choose a place of dying, we would not choose the hospital or the nursing home but our own home.” (Translated quote, D2)

Parliamentarians shared the conviction that once outpatient palliative and hospice care was made possible by appropriate legislation, most of the *palliative people* would arrange to be cared for and die at home. Parliamentarians indirectly admitted that a ‘minority’ of the *palliative people* might not prefer outpatient over inpatient palliative care. However, parliamentarians kept focusing on the large majority

of the *palliative people* who desire outpatient over inpatient care – which, according to them, is how it should be.

It should not be the objective to arrange that the last phase of life is always spend in inpatient facilities such as hospices. At this point, too, it is important that outpatient care comes first, and inpatient care comes second. If possible, people who are terminally ill should spend the last phase of their lives where they want, and this is in most cases their usual environment. (CDU/ CSU, D2)

From these results we can conclude that parliamentarians agreed on their portrayal of the preferences of the *palliative people* as self-determination in end-of-life (care) and being care for at home and of death as a process that would allow self-determination.

Unwanted claims about the palliative people: rejecting claims about cannabis use and making euthanasia preferences obsolete

The few attempts in which a parliamentarian tried to diversify the portrayal of the *palliative people* in terms of preferences were immediately rejected by other parliamentarians, judging the attempts to be controversial and therefore to be clouding the debate. This for instance happened in an attempt to portraying the *palliative people* to want to use Cannabis for pain-relief.

There is one more wish that has not been addressed in this debate so far. I hear this wish every time I visit a hospice and every time I talk to palliative care specialists. If you really want to help seriously ill patients and patients suffering from chronic pain, then I suggest to finally legalize Cannabis... [Interruption: “And you are talking about a depoliticized debate!”] (Translated quote, D4)

The attempt to portray the *palliative people* as wanting to use Cannabis for pain-relief was dismissed. The dismissive parliamentarian did not question as to whether it is ‘true’ that *palliative people* want to use Cannabis. Rather, the claim was framed as being inappropriate because of its political character. To parliamentarians it was important to conduct the debate in an *apolitical* manner. They repeatedly warned each other not to “abuse the debate for party politics” (Translated quote, D4) and kept reminding themselves that when talking about the very private matter of palliative and hospice care “political attacks are not appropriate” (Translated quote, D4).

Parliamentarians did not only reject claims about cannabis use but also about the possibility of palliative patients wanting euthanasia. The issue of euthanasia came up partly because parliamentarians used the topic of euthanasia to stress the importance of drafting a bill on palliative and hospice care. Acknowledging that some *palliative people* want the legal possibility to opt for euthanasia, parliamentarians argued that the implementation of palliative and hospice care removes the need of that preference.

[Many people share the] fear of an agonizing death. They are afraid of pain, shortness of breath and suffering. Because of this fear there is a desire for euthanasia or the possibility to have this option in order to escape suffering. (...) [It is] then the first and best answer to these worries to say: everyone in Germany (...) should have access to palliative and hospice care. (Translated quote, D4)

Controversial issues such as cannabis use and euthanasia were thus avoided by rejecting claims from the debate or making them obsolete as the drafting of the bill would eliminate certain preferences amongst the palliative people. Parliamentarians applauded themselves to have adopted a bill for the *palliative people* and to have turned the drafting of the bill into a moment of glory, a “*Sternstunde*”.

To me, it was exceptionally good (...) that all political parties were involved in the process of adopting the bill, and that no idea was rejected as a reflex response because it was issued by another political party. Instead, we asked: What is good? What makes sense? What is important for the people? I believe the Parliament to have benefited from this debate. That is why we can definitely call this debate a ‘*Sternstunde*’ (Translated quote, D7)

Discussion

To gain more insight into the multi-faceted nature of patient representation in policy making, it is important to study the representation work of different actors making representative claims (Saward 2010) about patients. This includes not only patient organizations but also elected representatives such as parliamentarians. In this paper we have directed our attention to the latter by studying elective patient representation performed by German parliamentarians in the context of adopting a bill on palliative and hospice care, focusing on what patient constituencies are invoked and how representative claims about palliative patients are debated among parliamentarians.

Results suggest that the phenomenon of elective patient representation is not only limited to *factual* patients but expands to *potential* patients. Turning ‘the people’ into palliative patients-in-waiting, parliamentarians constructed the constituency of the *palliative people* that absorbed the political presence of factual patients. It is constitutive for policy-making how constituencies are being constructed as establishing us-them distinctions shapes the course of the debate that is to come (Mouffe 2013, 2020). On the one hand, one can argue that making ‘us’ aware that becoming a palliative patient is a potential future is a means to induce solidarity with palliative patients and their care needs (Rorty 2009). On the other hand, one can problematize that the rolling of the people and palliative patients into one constituency contradicts the idea of giving voice to patients in health policy decision making. Parliamentarians equated the preferences of potential patients with those of factual patients. Departing from rather rosy projections of death that often dominate debates on end-of-life care (Cottrell and Duggleby 2016; Kastbom et al. 2017), parliamentarians voiced preferences based on their own anticipation rather than preferences derived from lived experiences. Yet the dominant idea on giving voice to patients centers upon incorporating the experiential knowledge of patients into decision making processes in order to improve the quality of policies (Van de Bovenkamp et al. 2010). This experiential knowledge builds on lived experiences and can differ between individuals. It can include the experience that being terminally ill restricts one’s own ability to act as a “self-determined customer” because of dependence and physical weakness (Seibel et al. 2014), or the experience that once care needs increase in the course of a palliative care trajectory, home does no more feel like home because of all the “medical equipment such as hospital beds and oxygen concentrators, along with health professionals visiting frequently” (Robinson et al. 2016), or the experience that despite receiving palliative care one might still desire euthanasia (Stutzki et al. 2014; Galushko et al. 2015).

Across party boundaries parliamentarians agreed upon portraying the *palliative people* as desiring self-determination in end-of-life (care) and using this self-determination in a particular way (to want to die at home and not want euthanasia for example) by framing these preferences as being natural. This implicitly suggests that someone who does not share these preferences has *unnatural* preferences

which should not be catered for in policy making. The same goes for the preferences of people wanting to use cannabis in the palliative phase. The parliamentarian who gave voice to this group was discredited by accusing her to misuse the debate on palliative and hospice care for party politics. People wanting euthanasia faded from sight as parliamentarians argued that one might *want* to have the legal option of euthanasia, yet that one does not *need* to have that option as palliative and hospice care is the answer to the fears and problems of terminally ill patients having this wish. In sum, parliamentarians emphasized the political preferences of the *palliative people* in such a way that the representation work of parliamentarians can not only be understood as a practice of giving voice but also as a practice of silencing voices.

Barring few exceptions – such as the contested desire for cannabis for reasons of pain relief – there was no controversy among parliamentarians regarding the portrayal of the *palliative people*. Self-determination in healthcare, outpatient care and disapproval of euthanasia are elements that are deeply embedded in German healthcare policy (Blank et al. 2018a; Rosenbrock and Gerlinger 2014; Borasio et al. 2017). While to parliamentarians those values were beyond controversy, to the literature they are not. The value of self-determination in healthcare has been identified as being intertwined with neoliberal thinking and has been problematized as utilization of consumerism to the healthcare sector that risks a responsibility shift from professionals to patients (Mol 2008; Mounk 2017). Authors problematize outpatient care as means of cost saving (Robinson et al. 2016) and argue for a larger political debate on the allocation of care responsibilities (Tronto 2013; Levitsky 2014). The framing of euthanasia and palliative care as antagonistic means has been identified as an argument frequently used by those who disapprove of euthanasia because of socio-political ideology and religiosity (Hurst and Mauron 2006; Bernheim et al. 2008).

The lack of competing representative claims contributed to covering up the diversity of patient preferences and experiences and the underlying political values that shaped the drafting of the bill on palliative and hospice care. The politicality of the debate did not become transparent as parliamentarians defined the political dimension of palliative and hospice care as controversial and by

consequence out of bounds. A debate offering “competing visions of the people to the people” (Runciman and Brito Vieira 2013) through competing claims could have forced parliamentarians to better justify their political demands and to unravel the political values that informed the drafting of the bill (Stone 2012).

Conclusion

Aiming to shed light on the under-researched field of elective patient representation, this study showed that parliamentarians not only make representative claims about patients but also about projected patients-in-waiting. German parliamentarians across party boundaries constructed the *palliative people* as wanting self-determination in end-of-life care and outpatient palliative care. Voices of patients not sharing these views or not in the position to share them or having controversial preferences such as cannabis use or euthanasia were silenced. Instead of putting forward different claims and debating them and thereby unravelling the political values that informed the drafting of the bill, parliamentarians used the constructed image of ‘the people’ to limit this debate. Future research should continue to look into representation as a practice of not only giving but also silencing voices, exploring what patient voices on lived experiences are brought to the fore in political debates and which ones are lost as they do not fit dominant political values.

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On dementia representation work

Dementia continues to be politicized. Politicization can be described as “shifting an issue into the sphere of politics” and ensuring it remains in that sphere (Selk 2021; Wiesner 2021). A specific type of politicization focusses on parliamentarians as political power holders and it is this so called *parliamentarization* (Palonen 2021) that applies to dementia. The UK’s Alzheimer’s Society, for instance, fosters the parliamentarization of dementia by offering dementia awareness sessions to parliamentarians, by supporting parliamentarians through a helpline and by providing parliamentarians with dementia information. The organization does so because they are convinced that members of the British parliament (MPs) “can play a vital role in championing the rights of people with dementia, in their local areas and in Parliament. Understanding and support from Parliamentarians, in addition to the influence that MPs have in their constituencies, can help make communities more dementia-friendly and ensure our national laws support them.” (Alzheimer's Society) Another campaign related to the parliamentarization of dementia was launched by a transnational dementia-specific advocacy organization. The organization invites parliamentarians to join the European Alzheimer's Alliance which “is a nonexclusive, multinational and cross party group that brings together Members of the European Parliament to support Alzheimer Europe and its members in making dementia a public health priority in Europe.” (Alzheimer Europe). The pharmaceutical industry have also encouraged parliamentarians to pay political attention to dementia – for instance by organizing roundtables that bring together parliamentarians and stakeholders “interested and involved” in dementia to discuss policy action (MSD 2019).

Scholarship disagrees about what to make of the parliamentarization of dementia. There are scholars who argue that the parliamentarization of dementia draws attention away from persons living with other (health) conditions and disorders and believe that persons living with dementia benefit from policies that are integrated with broader public health responses. They therefore reject pure dementia-

focussed policies for both of these reasons (Wu et al. 2014). Others see the parliamentarization of dementia as a chance for achieving compassionate laws that help persons living with dementia to lead independent lives for as long as possible (Behuniak 2010). This second group of scholars argue that parliamentarians' interest in the topic is kept alive and influenced from outside the parliament – as described above – and that ways must be sought to prevent that parliamentary attention being lost (Parker et al. 2014).

We are currently lacking empirical insight into the argument that the parliamentarization of dementia enhances the lives of persons living with dementia. The literature provides analyses on how actors – such as dementia-specific advocacy organizations – manage to get parliamentarians to pay political attention to dementia (Ballenger 2006; Beard 2004; Fox 1989), yet studies that show how that attention manifests itself in parliament are few and far between (Nedlund and Nordh 2015).

Recent advances in political science representation theory (Saward 2010; Rehfeld 2006; Disch 2011, 2015) make it a suitable framework for analysing the realities of the parliamentarization of dementia as it offers a formula for researching *what kind of attention* parliamentarians pay to people with dementia and *how* that parliamentary attention manifests itself in parliament. According to representative claims theory, political attention often comes in the form of a representative claim. Through a representative claim, claims-makers (in this case parliamentarians) raise a political demand, make a policy suggestion, or address a political problem and connect that demand, suggestion, or problem to the interests of a certain constituency – persons living with dementia, for instance. A representative claim entails a *portrayal* of the proclaimed constituency. Representative claims theory theorizes political representation in a constructivist manner, stressing the creative force of representative claims (Disch 2019). This means that claims-makers make a *construct* of the group they claim to represent politically visible. The constituency is portrayed as a group whose members share certain preferences, interests, and features (Ankersmit 2009; Alcott 1991). For this portrayal, claims-makers “rely on their own information and imagination” (Celis and Mügge 2018). Representation therefore does not mean mirroring but creating realities (Disch 2019), making plurality in political representation important so

that the individual – in this case the person with dementia – may choose the political presence they identify with best from a pool of different creations. Shedding light into the political attention that parliamentarians pay to persons living with dementia through the lens of representative claims theory thus means exploring how parliamentarians construct persons living with dementia as a constituency to be represented and what political demands and policy suggestions follow that construction. It means analyzing the political presence that parliamentarians create for persons living with dementia, to better understand how parliamentarians aim to enhance the lives of persons living with dementia.

This paper is focused on *how representative claims made by German parliamentarians feature persons living with dementia*. In Germany, different dementia-specific advocacy organizations exist. The literature suggests that plurality in representative claims about persons living with dementia is accounted for *outside* the parliament (Schicktanz et al., 2018). As explained before, plurality in political representation is important and it is up to this study to show whether plurality is also accounted for *within* the parliament. Other than in the UK or on the European level, German dementia-specific advocacy organizations do not foster the parliamentarization of dementia by launching initiatives that seek to motivate parliamentarians to turn their representative efforts towards persons living with dementia (personal communication with the head of the German Alzheimer's Association) – which points to national differences regarding the parliamentarization of dementia. This study therefore does not present universally valid insights that can be transmitted into every other parliament. It rather seeks to shape our ideas and to increase our sensitivity regarding the parliamentarization of dementia – still an under-researched area of political dementia studies – by analyzing data from the German parliament as an interesting setting.

Materials and Methods

The author conducted a qualitative textual analysis of parliamentary documents. Documents were collected using the search tool of the online archives of the German parliament, called the “Dokumentations- und Informationssystem für Parlamentarische Vorgänge”. The idea for the study

originated in early 2020. The keyword search focused on the years 2018 and 2019 to collect the most current data possible. The search put forth all documents that included at least one of the search items 'Demenz' (English: 'dementia'), 'dement' (English: 'demented'), and/ or 'Alzheimer'. As well as written parliamentary questions issued by political parties of the opposition and the answers to those questions provided by the government, the data set included plenary protocols of the *Bundestag*, which is the chamber of the German parliament that is elected directly by the German people. In sum, 56 documents were collected.

Table 1

List of 56 analyzed documents collected via the online archives of the German parliament

Number of publication	Date of publication	Number of publication	Date of publication
19/8	19.01.2018	19/88	20.03.2019
19/1039	02.03.2018	19/89	21.03.2019
19/1228	15.03.2018	19/9033	03.04.2019
19/23	22.03.2018	19/92	04.04.2019
19/24	23.03.2018	19/93	05.04.2019
19/1540	04.04.2018	19/95	11.04.2019
19/1544	04.04.2018	19/9880	07.05.2019
19/1763	20.04.2018	19/101	16.05.2019
19/34	18.05.2018	19/102	17.05.2019
19/2448	04.06.2018	19/10443	21.05.2019
19/3065	28.06.2018	19/10456	23.05.2019
19/42	28.06.2018	19/10481	23.05.2019
19/46	05.07.2018	19/11017	21.06.2019
19/3384	13.07.2018	19/11318	02.07.2019
19/3429	16.07.2018	19/11515	12.07.2019
19/4384	17.09.2018	19/12560	22.08.2019
19/4760	05.10.2018	19/12800	29.08.2019
19/5736	12.11.2018	19/113	13.09.2019
19/5815	16.11.2018	19/13394	23.09.2019
19/6072	28.11.2018	19/115	26.09.2019
19/6796	02.01.2019	19/116	27.09.2019
19/7014	14.01.2019	19/13813	08.10.2019
19/74	17.01.2019	19/14077	16.10.2019
19/7378	28.01.2019	19/14079	16.10.2019
19/78	01.02.2019	19/14216	18.10.2019
19/7519	04.02.2019	19/124	07.11.2019
19/84	22.02.2019	19/15389	22.11.2019
19/8498	19.03.2019	19/131	28.11.2019

The author performed a data analysis in a manner inspired by interpretive methodologies (Schwartz-Shea and Yanow 2012). Text passages were extracted that covered one or more search items. To avoid missing realities because of a rigid fixation on theoretical conceptualizations (Law 2007; Schaffer 2016), the analysis began with an extended familiarization of the data which was achieved by repeatedly reading each extracted text passage within its context – meaning the text that surrounded the extracted passage. Taking familiarization and representative claims theory (Saward 2010, 2019; Disch 2015) as a theoretical basis for the study, the author developed an analytical framework in order to be able to categorize each extracted text passage. The analytical framework included three categories: (1) representative claims about persons living with dementia, (2) representative claims about other groups that feature persons living with dementia, (3) and other. Within the first and second category, the author searched for recurring themes and logical patterns that contributed to answering the research question (Fujii 2018). The third category encompassed text passages that were identified as being irrelevant for this study because of offering no insight into representative claims made by German parliamentarians that feature persons living with dementia. For instance, one excluded document mentioned a national dementia-specific advocacy organization but had no substantive claims about persons living with dementia. The organization was included on a list of interest groups that had handed in a statement on the drafting of a bill on professional caregiving and nursing.

Being aware of the language challenges in qualitative research, the study followed recommendations aimed at reducing “the loss of meaning [in] cross-English qualitative research” (van Nes et al. 2010). The interpretation of data was performed in the German language and the translation of quotes was undertaken with the support of a professional translator.

Results

German parliamentarians rendered persons living with dementia politically visible in debates on a broad range of topics – such as in plenary discussions on guardianship, nutrition policy, urban development and asylum policy. However, political attention to dementia did not always come in the form of a

representative claim. Parliamentarians did not necessarily talk about persons with dementia every time they mentioned dementia or Alzheimer's disease. For instance, when discussing financial contributions to the European Union, a parliamentarian addressed advances in medical research on Alzheimer's disease to stress the importance of European research funding.

Without resources for European research funding, many important discoveries, for example in the field of cancer research, Alzheimer's disease research, would not have been made. What can we learn from this? There is, of course, a link between more EU funding on the one hand and better science on the other hand. (Translated quote, 19/102)

The parliamentarian neither mentions persons living with dementia directly nor implies that persons living with dementia (or others) are interested in medical research on Alzheimer's disease in particular or are backing German financial contributions to the European Union in general. Her statement thus does not count as a representative act. In the following, instances are presented in which parliamentarians embedded the creation of political presence for persons living with dementia into representative claims – about persons with dementia but also about other groups.

Representative claims about persons living with dementia

German parliamentarians made representative claims about persons living with dementia. For instance, parliamentarians stressed the importance of taking political action to protect persons living with dementia from violence in care practices. Similarly, when discussing data privacy, parliamentarians stressed that persons living with dementia needed to be protected from the commercial trade of patient records.

Persons living with dementia did not necessarily receive an exclusive political presence in such representative claims. Instead, parliamentarians added them to broader constituencies that encompassed different groups whom parliamentarians considered as being vulnerable.

People have the right to be cared for with dignity. (...) They often have several illnesses, they have depression or dementia, they have other impairments and disabilities. That is why we need specialist staff who are able to

provide professional care and rehabilitation, who have comprehensive medical knowledge at the forefront of science and who can organize and manage complex care programs. (Translated quote, 19/42)

It was a pattern that parliamentarians emphasized that persons living with dementia need and deserve protection and special attention and treatment because of their vulnerability. When discussing e-health, a parliamentarian emphasized the need to consider special measures for health informatic systems, given that persons living with dementia might not be able to remember their PIN. When discussing actions to counteract the health consequences of climate change, a parliamentarian demanded the introduction of a means of heat protection for “vulnerable groups, such as the elderly, the chronically ill, persons living with dementia and infants and young children” (Translated quote, 19/11515).

The theme of vulnerability not only led to demands that society needs to protect persons living with dementia but also to arguments that society needs to be protected from persons living with dementia. Consider the following example that occurred in the context of changes to legislation on voting.

To demonstrate the extent of the problem: In mid-2018, the German Alzheimer's Association stated that the number of persons living with dementia in Germany was around 1.7 million. As the disease progresses, a large number of these patients can no longer be expected to be able to make a conscious electoral decision themselves. The total number of people affected is increasing significantly with more than 300,000 new cases every year. (...) In order to protect the legitimacy of elections held in Germany, there must be effective precautions to prevent speculation that election results are being manipulated by the fact that a considerable number of absentee ballots from people who are no longer capable of making their own decisions are being filled out by third parties acting on their own will. (...) It is imperative that the new regulations also clearly define the limits of acceptable assistance, so that it is clear who is acting as an assistant and who is only shamefully exploiting a person with impaired abilities for their own interests. (Translated quote, 19/101)

The parliamentarian demands precautions regarding voting assistance for persons living with dementia. He makes a representative claim about persons living with dementia by arguing that persons living with dementia need to be protected from being ‘shamefully exploited’. Yet at the same time, he renders persons living with dementia politically visible as a danger to the public value of elections, substantiating his political demand by stressing the need to prevent electoral fraud and safeguard the legitimacy of

elections. In this line of argumentation, the large and growing number of persons living with dementia is framed as a problem and as constituting a burden. It was a recurring theme that persons living with dementia were made politically visible as a burden on society at large or on distinct groups in particular – especially in representative claims that featured persons living with dementia but were made about other groups, as will be shown in the next section.

Representative claims about other groups that feature persons living with dementia

Persons living with dementia were also made politically present in representative claims about other groups. In such instances, parliamentarians used the political presence of persons living with dementia to argue for the wants and needs of these other groups, without explicating what they considered to be the interests of persons living with dementia on the matter.

A single diagnosis can turn your life upside down. Just think of the long, hard journey that comes with cancer treatment, or what it's like to see a loved one with dementia gradually turn into a stranger. That is why progress in health research is so important for people's lives. As politicians, we play a pivotal role in ensuring that the discoveries made in laboratories reach doctors' surgeries, hospitals and people's homes. (Translated quote, 19/84)

Using the metaphor of the stranger to highlight the burden that dementia is putting on those who witness a person developing dementia, the parliamentarian exclusively directs her representative efforts towards those who “love” a person developing dementia.

Another example highlights that within representative claims about other groups, parliamentarians repeatedly rendered persons living with dementia politically visible as a burden on others and as causing problems.

Like many people in this House, I once did a day's internship in a care facility as a member of parliament in my constituency. I arrived there in the morning and then the head of the nursing service asked me if I had ever dealt with persons living with dementia in my life. I said with a bit of pride: "Yes, during my civilian service many years ago, I visited people with dementia at home and tried to support them". The nurse manager said: "Then you got to know the simpler cases still with their families. Here, in the inpatient facility, we have the difficult

cases". I want to confess openly here: After half a day of practical training I was quite, let's say, stressed, because it is very challenging to work with people whose personalities have really changed a lot, some of whom are very aggressive, although they cannot help it. But, ladies and gentlemen, the care workers in this country, they don't do it for a day's internship, they do it every day. Therefore, it is time that we stop just talking and instead act now and make sure that these people get better wages and better working conditions. (Translated quote, 19/115)

Directing his representation work towards professional caregivers and nurses, the parliamentarian uses the political presence of persons living with dementia to strengthen his political demand for higher wages and better working conditions. While better wages and better working conditions for professional caregivers and nurses could lead to better circumstances for persons living with dementia, this was not part of the representative claim made. Instead, the parliamentarian argued that persons living with dementia are very challenging to care for – so challenging indeed that professional caregivers and nurses deserve better wages and better working conditions as compensation for the burden that they are facing.

Discussion

The parliamentarization of dementia involves representative claims. The study revealed that German parliamentarians pay political attention to persons living with dementia in two ways. First, they rendered persons living with dementia politically visible in representative claims about persons living with dementia. Second, they created a political presence for persons living with dementia in representative claims about other groups – such as family members of persons living with dementia, nurses and other professional caregivers. In representative claims about persons living with dementia, parliamentarians voiced what they considered to be the interests of persons living with dementia on that matter. In representative claims about others, parliamentarians enacted political visibility for persons living with dementia to argue the wants and needs of the others instead of the persons living with dementia.

In representative claims about persons living with dementia, parliamentarians portrayed them as vulnerable members of society in need of protection. By focusing on the argument that persons living

with dementia *need to be protected* (e.g. from heat, the commercial trade of patient records and electoral fraud), parliamentarians used the theme of vulnerability in a patronizing manner. Their representation work thus does not align to the idea that a political understanding of persons with dementia as vulnerable citizens fosters compassionate law making due to an increased sensitivity regarding the “uncertainty of whether or not a person with deteriorating mental capacity can protect his or her own interests” (Behuniak 2010). It can rather be understood as an example of socio-political practices and discourses that disempower persons living with dementia and that complicate or even prevent those persons living with dementia from participating and shaping their lives in a self-determined manner (Bartlett and O'Connor 2007; Nedlund and Nordh 2015; Baldwin 2008; Birt et al. 2017). Given the risks of the Covid pandemic for persons living with dementia not only regarding the disease and but also regarding associated public health policy responses (such as lockdowns) (Rajagopalan et al. 2021), future studies may explore related parliamentary debates to better understand how parliamentarians make use of the themes of vulnerability and protection and whether persons living with dementia ultimately benefit from this or not.

In representative claims about other groups, parliamentarians portrayed persons living with dementia as a burden and as causing problems, and in doing so contributed to keeping alive derogatory and exclusionary portrayals that have featured in dementia studies since the 1990s (Kitwood 1997). Scholars continue to argue that portraying persons living with dementia like this can cause destructive feelings in persons living with dementia and it risks leading to a delay in seeking help and a withdrawal from social life (O'Sullivan et al. 2014; Nguyen and Li 2020). Related metaphors, such as the one of the ‘stranger’ used by a parliamentarian, have a similar effect. The metaphor of the stranger suggests that the person as they were *before* dementia is “in some fundamental way already gone despite the unnerving persistence of the body” (Ballenger 2006). It implies that the person *before* dementia is a different person than the one *with* dementia (Sabat and Harré 1992). Using the metaphor of the stranger amounts to an invalidation of persons living with dementia, and could potentially lead to disrespectful behavior of others toward persons living with dementia as well as to poor care practices,

including the objectification of persons living with dementia (Innes 2009)., A national dementia strategy was adopted by the German parliament in 2020 (Nationale Demenzstrategie 2020), later than in most other Western industrialized countries (Fortinsky and Downs 2014; Nakanishi and Nakashima 2014). The strategy, too, emphasizes the importance of ending stereotypical and potentially stigmatizing dementia portrayals. The strategy was adopted after the study period and future research may look into the effect of national dementia strategies (for Germany but also for other countries) on the parliamentary representation of persons living with dementia, in order to further our understanding into how the parliamentarization of dementia enhances the lives of persons living with dementia.

On the plus side, parliamentarians did not strive for “pure dementia-orientated policy” responses as feared by scholars (Wu et al. 2014) but rather embedded their political attention for persons living with dementia in broader parliamentary debates and therefore made persons living with dementia matter beyond healthcare legislation. On the downside, there was little plurality in their representative efforts – both in representative claims about persons living with dementia as well as in representative claims about groups that feature persons living with dementia. Both types of claims were focused one-dimensionally on the impairments and diminished capacities of persons living with dementia. Such a focus leads to an othering of these persons. Othering means that persons living with dementia are understood as differing from others in an *essential* and *fundamental* way (Fletcher 2019). It means that “similarities and differences among people with dementia and between them and other people” are overlooked and actively made invisible (Gerritsen et al. 2018). The fact that parliamentarians clustered persons living with dementia together with other groups deemed vulnerable – such as children – does not mitigate the problem. It rather increases the problem, as it contributes to the othering of children as well. Similar to the work taking place in dementia studies, scholars are also striving to generate more political sensitivity to prevent children from being portrayed as a homogenous group and from being understood as lacking decisional capacity (Holzscheiter 2016). In general, othering risks diminishing solidarity as it draws a clear distinction between *us and them*, and – in doing so – paves the way for exclusionary practices (Rorty 2009). In short, the political attention that persons living with dementia

received came at the price of othering – which undermined the potential of the parliamentarization of dementia to enhance the lives of persons living with dementia.

Creating awareness among parliamentarians that persons living with dementia make up a growing share of their electorate may help to improve the way parliamentarians render persons living with dementia as politically visible. Scholars stress the importance of not denying persons living with dementia their voting rights (Behuniak 2010; Kohn 2014) and in Germany, no legal discrimination of voters living with dementia exists compared to other voters (German Alzheimer's Association 2019). Parliamentarians are aware of their dependence on being re-elected (Saward 2010; Rehfeld 2005) and the realization that persons living with dementia are also voters might convince them to restrain from using the political presence of persons living with dementia to advocate for the interests of others. Given that scholars do not take the parliamentarization of dementia for granted (Parker et al. 2014), such an understanding might also contribute to securing long-lasting political attention towards persons living with dementia. What is more, it might motivate parliamentarians to create a political presence for persons living with dementia that is more balanced and multi-dimensional and that neither focuses exclusively on impairments and diminished capacities nor uncritically aligns to the “‘living well’ discourse in contemporary Western society” (McParland et al. 2017). Finally, it might encourage parliamentarians to engage more with persons living with dementia, to discover which political demands persons living with dementia want parliamentarians to raise in their name. There is too little known about how persons living with dementia want to be represented (Sonnicksen 2016a, 2016b); for instance on whether they identify with being rendered politically visible as vulnerable persons (Bartlett and Brannelly 2019). Dementia advocacy organizations are often seen as those actors in the know about the political interests of persons living with dementia. However, some studies advise being more alert and skeptical of such organizations, as they often draw on the accounts of family members to formulate apparent political needs and wants of persons living with dementia instead of directly interacting with such persons themselves (Beard 2016). It is thus important that future studies also look into the representation training that dementia advocacy organizations offer to parliamentarians – as described in the

introduction – and explore what kind of political representation and parliamentarization of dementia such training leads to.

Conclusion

In the German parliament, persons living with dementia receive a one-dimensional political presence as vulnerable members of society who need to be protected by the same society that their existence is putting a burden on. Such representational practices do not meet scholarly expectations regarding the parliamentarization of dementia. This study succeeded in providing insights that contribute to a better understanding of what kind of parliamentary attention may indeed enhance the lives of persons living with dementia. It is important that parliamentarians avoid othering persons living with dementia when rendering them politically visible. It is also important that they do not only create a political presence for persons living with dementia to advocate the interests of others. This paper concludes by inviting parliamentarians to view persons living with dementia as voters and to modify their dementia representation work so that it becomes more appealing to persons living with dementia. This would require parliamentarians engaging with persons living with dementia and learning about how they would like to be rendered politically present in parliament.

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Discussion

The interdisciplinary endeavor of *Political Patient Studies* is concerned with the question whether, to what extent, and how patients matter to politics. Drawing on recent accounts of political science representation theory (Saward 2010; Disch 2019), I conceptualized practices of voicing patient preferences in political decision making processes as acts of representation and analyzed ways in which patients are rendered audible and visible in the political arena. In what follows, I bring together the findings of my four studies and discuss them in terms of their scholarly value. This chapter addresses the questions *how political patient representation is performed, and what effects do the representative efforts of patient organizations and parliamentarians have in terms on patients' political presence in the field of public health policy*. It concludes with a reflection on the limitations of my work along with suggestions for future research.

Problematizing performances of political patient representation

My dissertation started by conceptualizing representation as a practice that channels the wants and needs of patients to the public political sphere (chapter 1). This theorization, however, does not fully capture the realities of political patient representation. According to representative claims theory (Disch 2015; Saward 2009, 2010), a representative claim entails a subject (the representative, in this case a PO or a parliamentarian) and an object (the representees, in this case patients, who are at times added to broader constituencies that also encompass others as well as patients, such as family members or children; chapter 3 and 5) and a verb. That verb signifies the representative's performance – which is, according to theory, about the construction of a constituency, about the reading *in* of political interests into the constituency, and about the introduction of oneself as a representative of the constituency. Yet political patient representation involves more than that as POs and parliamentarians were also found to attach their constructed patient constituencies to a distinct political demand, suggesting a particular

political solution to the apparent patients' unmet wants and needs. The constituency constructed and the political demand form a symbiotic relationship. That is, the constituency exemplifies the political argument that the representative is trying to make, it carries the political value that the representative is holding, it substantiates the political change that the representative requests. Neither POs nor parliamentarians perform political patient representation as *spokespersonship*; they do not attempt to pass on or echo political demands that have been formulated by patients. Rather, they make it their own achievement that they came up with a political demand that contributes to solving patient problems – which they are, allegedly, *in the know* of (chapter 3, 4, 5). Given that individuals are often unable to “view personal troubles as political issues” and do not understand their unmet and “longstanding ‘private’ needs or interests as matters of legitimate public deliberation and decision making” (Levitsky 2014), one might argue that political patient representation appears as a practice that nurtures political consciousness. However, the worth and value of performing political patient representation this way depends on *whose* interests inspire a political patient representative to develop a certain political demands, *how* they learn about apparent patient preferences, and on what grounds they base their claim of *being in know* about the wants and needs of patients.

Emphasizing personal contact with patients is a central basis for representative claims about patients used by POs and parliamentarians alike – and, as shown by the literature, also by representatives who make representative claims about other constituencies, such as children, Muslim women, etc. (Montanaro 2012; Severs 2012; Severs et al. 2013; Celis and Mügge 2018; Holzscheiter 2016). A German parliamentarian, for instance, emphasized her regular visits to hospices when demanding the legalization of cannabis for reason of pain relief (chapter 4). POs, too, highlighted the importance of personal contact with patients, arguing that staying in close contact with patients is the best way to learn about pressing problems that require a political solution. POs were found to seek patient contact at public events (such as a fair or protest marches), at workshops and trainings, via discussion fora (such as standing working groups or round tables), and by regularly visiting individual patients who can no longer participate in the before mentioned activities due to the progression of their disease or condition

(chapter 3). This, however, does not mean that political patient representatives always specifically revealed or disclosed the sources and procedures that fed their claimed representation expertise. For instance, parliamentarians who made representative claims about patients living with dementia rarely specified their contact to patients living with dementia (chapter 5).

As well as personal contact, there are also other claims-bases that political patient representatives ground their representative efforts on. For instance, they base their representative claims on published scientific research results. Scientific research results count as authoritative knowledge which possess convincing power in the sense that the representative appears to be voicing wants and needs of the representees that are *evidence-based* (Brown 2009). Many scholars advocate the inclusion of empirical insights on patient preferences into health policy decision making (Akrich 2010; Epstein 1995, 2008; Pols 2013; Van de Bovenkamp and Zuiderent-Jerak 2015) and scholars found POs not only refer to study results to convince their audience that their political demands are in line with patients' wants and needs but even conduct studies on their own (Rabeharisoa 2003, 2006; Rabeharisoa et al. 2014). Yet my thesis found instances in which claims were based on study results in a rather paradoxical way. Throughout the parliamentary debate on the German bill on palliative and hospice care, it was considered sufficient by parliamentarians to refer to a study that explored preferences regarding the place of dying of the overall population in Germany (chapter 4). Due to the construction of the people as palliative patients-in-waiting, it was not deemed necessary to add study results specific to the experiences and preferences of *actual* palliative patients. Moreover, it also became possible for German parliamentarians to base their representative claims on *mirroring*. "A mirroring claim is based on descriptive similarity between the claimant and the constituency he or she claims to speak or stand for" (Saward 2010). Similar to other "desperate attempts by the political class to portray itself as similar to so-called ordinary people" (Castiglione and Pollak 2019a), German parliamentarians put forward the argument that they, too, are patients-in-waiting, resembling their worries and hopes to other members of the constituency. It is deemed important that the experiences of patients find their way into health policy decision making as this is expected to result in policies that are better equipped to address the unmet needs of patients

and to lead to the creation of a patient-centered healthcare system – which is on the agenda of many governments, including the German one (Forster and Kranich 2007; Winter and Winter 2018). It is thus the *experiential* knowledge of patients that is of relevance, yet parliamentarians did not add experiences about what it is actually like to be palliative patients to the debate but established anticipation as a relevant source for developing a bill on palliative and hospice care. In doing so, German parliamentarians took the core ideas of both mirroring and referring to study results to the absurd.

The interweaving of the results of my four studies suggests that POs and parliamentarians perform political patient representation in a unifying manner. It becomes apparent that political patient representation implies that patients (plural) are effectively absorbed by the construction of *a* or more precisely *the* patient constituency. Both parliamentarians and POs rendered patients politically visible and audible as a homogenous group – which, as well-established by the literature, they are not (Maguire and Britten 2017; Madden et al. 2021; Epstein 2008; Lander et al. 2016). Legislation could be understood as reinforcing the missing plurality in political patient representation in that it does not require patient representatives to do justice to the diversity among patients; neither so in Austria nor in Germany or in other countries (Chapter 2). Ultimately, there is often only a *single* political presence created for patients. As shown by the literature, many makers of representative claims tend to worry that it may weaken their position if they admit that there are also constituents who do not agree with their representative efforts (Wolff 2013) and it appears that political patient representatives, too, worry that giving justice to the diversity among patients may come at the expense of those patients who ultimately profit if they are able to push through their political demands. For reasons of persuasion, they seem to be convinced of the necessity to create a unifying political presence for patients.

The phenomenon of a single political presence for patients is not only limited to the performance of distinct patient representatives but also unfolds contextually. As described in chapters 4 and 5, patient portrayals that entered the political debate via the representation work of various parliamentarians were rarely contradicted, the representative claims made about patients were seldomly debated, and the patient constituencies constructed by some parliamentarians were not de-constructed by other

parliamentarians. Representative claims theory suggests that the audience, meaning those who witness a representative claim, has the opportunity to reject representative claims and thus to alter the political presence of a certain group (Saward 2010; Guasti and Geissel 2019). However, parliamentarians who were witnessing the representative claims about patients made by other parliamentarians hardly made any use of this opportunity. The ones that did were discredited and put down (for example the parliamentarian who advocated the legalization of cannabis on the basis that palliative patients desire so for reasons of pain relief. She was accused of making such a representative claim for the self-serving reason of party politics; chapter 4). The reasons for the reluctance of parliamentarians not to question or critique representative claims that render patients politically present as a homogenous group may be manifold, ranging from the desire not to complicate a political debate and to avoid touching difficult and politically controversial issues (such as euthanasia; chapter 4) to uncritical acceptance of unifying assumptions about patients (such as associating dementia exclusively with cognitive impairments and diminished intellectual capacities; chapter 5).

The fact that patients usually, and necessarily, differ leads to a reflection of the consequences of the missing plurality in political patient representation for patients who do not share the wants and needs of the patient constituency constructed. It appears that only those patients who identify with the single political presence matter to politics. But what about the other ones? I argue that the creation of a single political presence for patients contributes to legitimizing only certain patient preferences while masking the fact that patients differ in their wants and needs. Rendering patients politically visible and audible as a homogenous group within which all members share identical wants and needs conceals the diversity among patients. A single political presence for patients may contribute to creating a reality out of sync with the needs and wants of those patients who do not comply with that portrayal. The literature provides an instructive example that substantiate my problematization of the missing plurality in political patient representation. The Italian law 180/78 enforced the closing of psychiatric “asylums” and fostered the introduction of community-based mental health services (Girolamo et al. 2008). The law addressed the urgent necessity to overcome the harmful “practice of long hospitalization periods

and treatments that secluded the patients from their families and from society as a whole” (Fusar-Poli et al. 2011). However, the design of the law was informed by a certain understanding of a patient with schizophrenia, who was depicted to be better off served in the community for therapeutic reasons (Villacañas de Castro 2021). As it turned out, the law caused problems by ignoring patients who needed inpatient care provision and by forcibly returning patients to their families because of not “offering options and alternative ways of treatment and management of patients with mental illness in the community” (Russo and Carelli 2009). The example of the Italian law demonstrates the problematic nature of legislation that is not equipped to catch the multiple actualities of healthcare and that overlooks the diversity among patients. I maintain that political debates that miss plurality in patient representation and instead focus on a single political presence for patients risk creating policies that benefit certain patients but at the same neglect or even harm others.

My thesis departed from the theory-based matter of concern that not everyone who claims to be voicing the interests of patients should be listened to. The reality of political patient representation is confusing and the answer to the question on whom to listen to (and whom not to) depends on the basis that political patient representatives ground their representative claims on (direct contact with patients, empirical evidence into the experience of patients, etc.) as well as on the democratic quality of their representation work. My findings further invite an expansion of the matter of concern. We do not only need to wonder about whom we should listen to but also how so. My results emphasize the importance of questioning any representative claims about patients and the patient constituencies constructed along the way. Rather than problematizing we need to become (more) appreciative of competing claims about patients as for without them political patient representation results in a *standardization* of patients. My problematization should not be read as an attempt to discredit everyone who performs political patient representation. On the contrary, by offering guidance on how to distinguish those to whom we should lend our ears from those better not listened to, my dissertation applauds patient representatives who put much work into developing policy positions that address the politically unmet needs of certain but certainly not all patients.

Limitations of my thesis

The findings of my dissertation do not allow to conclude that political patient representation as a rule takes shape as described. My analysis focused on political patient representation in its verbal enactment, and, in doing so, ignored the visual dimension of representation – such as pictures of patients living with dementia used by parliamentary-adopted National Dementia Strategies (Chow et al. 2018). As well as POs and parliamentarians, there are further actors who make representative claims about patients – such as “senior administrators, service strategists”, agents of the pharmaceutical industry, professional societies of physicians, nurses, and other healthcare professionals, etc. (Van de Bovenkamp and Vollaard 2018; O'Donovan 2007; Garpenby and Nedlund 2020; Kreindler 2015). These groups also make representative claims about patients, which may unfold differently and may be constrained by other influences. This may also be the case for representative claims made by other POs and parliamentarians, inside and outside the countries covered by my dissertation, or even with claims by the exact POs and parliamentarians included in my studies that are made at a later date. As described in the introduction, my research never intended to provide universally valid insights. It rather aimed to offer a *fresh* perspective on practices of making patient interests matter to politics and succeeded in doing so by offering genuinely novel insights that were missing in the existing literature.

My results do not indicate the magnitude of the phenomenon of a single political presence for patients. That is, the findings do not claim the phenomenon to be the biggest or most pressing problem attached to representative claims about patients. Studies into different settings may discover further and potentially more severe problems. This, however, does not hamper the relevance and necessity of problematizing the missing plurality in political patient representation and its potentially far-reaching consequences in terms of health policy making that I discussed earlier.

My analysis does not suggest that if only a little more justice were to be done to patient diversity, patients would matter *enough* to politics. I learnt that German parliamentarians – who have been criticized for paying too little attention to patients (Rosenbrock and Gerlinger 2014) – make representative claims about patients in political debates on a broad range of topics, yet this does not

mean that patient preferences are considered in parliament whenever needed. That Austrian POs, who are not as experienced in political activism as Dutch POs (Baggott and Forster 2008; Forster 2015, 2016; Rojatz and Forster 2017; Etgeton 2009; Van de Bovenkamp 2010; Van de Bovenkamp and Vollaard 2018), were found to engage in political patient representation may contribute to patients being politically covered in *more* decision-making processes, yet it does not guarantee that they are covered in debates of the greatest urgency. Not paying attention to whether the political presence of patients ousts the political presence of others (remember that German parliamentarians turned the people into patients-in-waiting and not into informal caregivers-in-waiting), my analysis does not rule out that, at times, patients may also matter *too much* to politics.

Future research

Reflecting upon the limitations of my thesis, I have already made some suggestions for future scholarly work – such as the suggestion that studies may shed light onto the patient representative efforts of actors different than POs and parliamentarians. One might, for instance, combine representative claims theory with the efforts of Science and Technology Studies to explore the political representation work of scientists and scholars. Within Science and Technology Studies, many theoretical frameworks exist that offer analytical guidance for exploring and problematizing the role of scientists and scientific advice in politics and democracy (Maasen and Weingart 2009; Bogner and Menz 2010; Bijker et al. 2009). I suggest that representative claims theory is equipped to catch realities of “politicized science and scientized politics” (Brown 2009) that were are currently missing. Covid-19-policy making qualifies as an interesting setting to explore entanglements of scientific and political claims, to unravel what constituencies scientists invoke to underpin their advice for politics, and to put to test the distinction or rather the distinguishability between political and scientific representation.

“Health may (...) be an expanding field for ‘representative claims’” (Mattila et al. 2019) and it is therefore important to expand the research agenda to family members and other others whose private

lives are affected by health policy decision making (Kofahl and Lüdecke 2012; Levitsky 2014). They, too, risk being excluded from being considered in political decision making as well as from being covered by legislation. The affected interest principle holds that “those potentially affected by a collective decision should have opportunities and capacities to influence that decision (proportional to the extent to which they are affected).” (Montanaro 2012) Against this principle, family members and others affected, too, should matter to health politics – and to its study thereof.

Exploring the kind of political presence German parliamentarians create for patients living with dementia led my thesis to find that the act of creating political presence does not equal the act of representing, that being made politically present does not mean being represented (Chapter 5). So far, representation theory occupies the concept of political presence, entangling it with representation (Castiglione and Pollak 2019b). Yet it seems appropriate to disentangle both concepts. The representation literature emphasizes that not every political demand comes in the form of a representative claim and that not every political action should be understood as being done *on behalf* of a certain group or in their name (Zicman de Barros 2020; Wilde 2013). Political demands exist that do not explicitly refer to any group: “More park benches are needed” (Guasti and Geissel 2019). Other political demands can be interpreted as implicit representative claims, in that the makers of the political demands do not explicitly claim to represent the group mentioned in the same breath as the political demand: “The reform is needed to improve children’s education” (Guasti and Geissel 2019). I argue that implicit representative claims and explicit representative claims are similar in that the group invoked by the claim receives a political presence as beneficiaries of the claim. Yet, as shown by my research, it is also possible that a group is being rendered politically audible and visible in representative claims about *others*. In such cases, the group receives a political presence not as beneficiaries but as a carrier for a political demand that others will (or at least are supposed to) benefit from – as uncovered by my study on the representation work of parliamentarians towards dementia (chapter 5). I suggest that the concept of political presence deserves more attention and a more thorough theorization. Such a theorization then might help us to gain a better understanding of when and why some groups in political

discussions and styles of argumentation are framed as being worthy of representation and as deserving of political support, whereas other groups end up being rendered politically visible and audible as citizens of secondary importance, with a political presence sans representation.

Concluding remarks

As described in the introduction, political science has been criticized for contributing too little to the broader field of social science health research (Carpenter 2012). The critique holds that political scientists only inquire health to advance their discipline's theories and that they do not join the interdisciplinary quest that strives for a better understanding of health politics and policy making (Noweski and Engelmann 2006; Gagnon et al. 2017). In closing, I would like to respond to the critique. Not only political science benefits from strong political science theories. Political science offers many theorizations that are of great analytical utility for the ever-growing field of interdisciplinary health research – for the instance on democracy, on politization and depolitization, on the situatedness of the public and the polis, on relationships of power, on antagonisms and conflicts, on inclusion and exclusion, on equality and liberty, and the like. Political science theorizations are free to draw on for everyone who aims at studying health and healthcare. The manuscripts of my paper-based thesis have been published in and submitted to interdisciplinary health journals. Hopefully they contribute to attracting more health researchers from different disciplinary backgrounds (within social science and beyond) to get inspired by political science's accomplishments.

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Eidesstattliche Erklärung

Ich erkläre hiermit an Eides statt durch meine eigenhändige Unterschrift, dass ich die vorliegende Arbeit selbständig verfasst und keine anderen als die angegebenen Quellen und Hilfsmittel verwendet habe. Alle Stellen, die wörtlich oder inhaltlich den angegebenen Quellen entnommen wurden, sind als solche kenntlich gemacht.

Die vorliegende Arbeit wurde bisher in gleicher oder ähnlicher Form noch nicht als Magister-/Master-/Diplomarbeit/Dissertation eingereicht.

27.12.2021

Datum

Unterschrift

Übersicht über die Manuskripte

Chapter 2	
Title	Legislating Patient Representation: A Comparison Between Austrian and German Regulations on Self-Help Organizations as Patient Representatives
Published in	Journal of Bioethical Inquiry, 2018 Sep; 15(3):351-358. doi:10.1007/s11673-018-9864-7. PMID: 29968017
Co-Authors	Daniela Rojatz, Hester van de Bovenkamp
Contributions	Julia Fischer developed the idea for the study. As joint first authors, Julia Fischer and Daniela Rojatz contributed equally to the implementation of the research, and to the writing of the manuscript. Hester van den Bovenkamp provided critical feedback on the interpretation of data and on the writing.

Chapter 3	
Title	The challenge of democratic patient representation: Understanding the representation work of patient organizations through methodological triangulation
Published in	Health Policy. 2019 Jan; 123(1):109-114. doi: 10.1016/j.healthpol.2018.11.011. PMID: 30528657
Co-Authors	Hester van de Bovenkamp
Contributions	Julia Fischer (first author) developed the idea for the study, designed and implemented the research, and wrote the manuscript. Hester van den Bovenkamp provided critical feedback on the interpretation of data and on the writing.

Chapter 4	
Title	Constructing the palliative people: On the representation work of German parliamentarians
Submitted to	Health Care Analysis
Co-Authors	Hester van de Bovenkamp, Roland Bal
Contributions	Julia Fischer (first author) developed the idea for the study, designed and implemented the research, and wrote the manuscript. Hester van den Bovenkamp and Roland Bal provided critical feedback on the interpretation of data and on the writing.

Chapter 5	
Title	The political presence of persons living with dementia in parliament: A qualitative study into the dementia representation work of German parliamentarians
Submitted to	Journal of Aging Studies
Co-Authors	None
Contribution	Julia Fischer developed the idea for the study, designed and implemented the research, and wrote the manuscript.

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