Exploring the Challenges of Dementia for Democracy

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Abstract

Around the world, millions of people suffer from dementia. Moreover, incidence and prevalence will increase significantly in years to come. While research has proliferated in multiple fields in the last few decades, dementia has been drastically neglected in the context of democracy thus far. This is surprising, as there is a multitude of democratic theoretical issues richly analyzed and conceptualized in political science, but strikingly little to be found with regard to the challenges posed by and for citizens with dementia. And yet, with dementia increasingly affecting societies in all regions of the world, citizens with dementia may become a veritably superlative illustration of political inequality. The current situation and the projected developments require us to reflect on how participation and inclusion are fundamentally challenged by Alzheimer’s and other dementia-related conditions. Accordingly, I propose to explore democratic implications and the emerging deficit for societies where millions of citizens are and will be de facto excluded from political processes. As will be demonstrated, this applies not only to elections, but also non-conventional and participatory-oriented concepts such as deliberative democracy, which, barring necessary adaptations and accommodation, could even exacerbate rather than ameliorate inclusion and participation for individuals with dementia. Finally, I also provide outlooks for potential avenues of ensuring democratic participation to an ever growing group of citizens.
1. Introduction

Dementia comes close to home for most people in one way or the other, whether by being a directly affected person, related or befriended to or caring for individuals with dementia. This bears enormous relevance on account of demographic transitions of societies around the world. Given the lack of curative treatment to date, the trends of increasing incidence and prevalence of dementia will only continue (Alzheimer’s Association 2013; Hampel et al. 2011; Wimo, Winblad and Jönsson 2010). The public and academic salience as much as research on dementia in multiple fields have proliferated tremendously over the last few decades, unsurprisingly in light of the demographic developments. Treatment and care but also societal inclusion and welfare rights constitute perhaps the utmost priorities in dealing with dementia. Nevertheless, what is surprising, if not troubling, is how little attention has been paid to democracy and relevant challenges in relation to dementia, especially in the field of political science. At the same time, research connected to democratic theory of all sorts has contributed an abundance of studies on various democratic challenges, problems and potential remedies, from improving inclusion and participation to redressing underrepresentation of citizenries as a whole or a vast diversity of groups. The same cannot be said, however, with regard to citizens with dementia.

Democracy encompasses a wide spectrum of meanings and arrangements in theory and practice. Nonetheless, at the base of any democratic government or theory lies equality, whether explicitly or implicitly. Among many things, this implies that all citizens are entitled to inclusion and thus must have opportunities to participate. These democratic demands rest upon in turn such notions as autonomy and both individual and collective self-determination. Inclusion can become complicated in practice on the other hand for multiple reasons or due to different circumstances. They may be situational, such as residing outside the country of citizenship for a time, or more long-term, such as with certain physical disabilities. In many cases, accommodations can and usually are made, such as allowing mail-in ballots or voter
assistance in polling stations. In the context of dementia and democracy however, the issue of inclusion is complicated by the issue of *includability* on account of diminishing cognitive capacity in line with the progression of dementia. This may touch upon questions of legal competence and thus eligibility according to many electoral laws, as well as open up sensitive issues of vulnerability and the integrity of the voting act but also the citizens themselves. From the outset, when approaching dementia from a democratic perspective, we face – and indeed must finally deal with – questions of how to uphold democratic representation and inclusion for citizens living with dementia. Accordingly, it is necessary to explore the challenges of dementia for democracy.

Addressing these questions requires us to reflect on many common, seemingly self-evident concepts and rules and, as the case may be, rethink how protection, adaptation and accommodation may be achieved. To this end, the following will first delineate several basic concepts and principles of democracy tied to representation, inclusion and equality. Without revisiting the entirety of democratic theory, the purpose is to establish an analytical framework for exploring and problematizing challenges of dementia in a democratic context. Building upon this, a series of democratic implications and the emerging deficits will be analyzed. As will be demonstrated, they apply not only to elections, but also non-conventional and participatory-oriented concepts such as deliberative democracy, which, barring necessary adaptations and accommodation, could even exacerbate rather than ameliorate marginalization for individuals with dementia. Against this backdrop, I develop in a next step an initial (and by no means exhaustive) outline for potential avenues for democratic reforms. Finally, the paper concludes with an outlook for moving forward in research endeavors to ensure democratic participation to an ever growing group of citizens.
2. Theoretical framework: Democratic problems and promises of equality

There are a number of tensions inherent to democracy. For one, they may derive from the empirical circumstances of a variety of forms of government predisposed to pursuing distinct democratic ideas, for instance those based more on a model of competition and alternation in government of majority parties or those more geared toward fostering cooperation, inclusion and consensus seeking (see e.g. Lijphart 1999). Aside from the varieties analyzed in comparative government, tensions emerge more fundamentally from the various principles democratic government is committed to and that cannot be realized, certainly not fully, simultaneously. Rule of the people has quite different implications for the democratic triad of government for, of and by the people, which does not reveal any particular set of institutional and procedural arrangements (see e.g. Sartori 1987). Nonetheless, it is still possible to establish some basic and necessary principles required of democracy. They may be construed in multiple ways, from participation and contestation (Dahl 1971), accountability and popular sovereignty to good governance, inclusion, representation and responsiveness (see e.g. Gerring and Thacker 2008; Kaiser et al. 2002; Lundell 2011; Schmitter and Karl 1991). The overarching component or ‘common denominator’ of democracy, we may argue, though is a presupposition of equality, which comprises the basis for a number of criteria (see e.g. Dahl 1998) and without which democracy of any shape or size would lose its meaning.

It is precisely equality that represents a ‘promise’ of democracy (Jörke 2010) that is likewise responsible for a number of democratically immanent ‘problems’. Among other things, democratic governments and societies are predisposed to solve problems and critically reflect on socio-political conditions from a particular perspective, namely with regard to the fulfillment of democratic principles and to seek a better realization of them. This is not only normatively consequential but also demonstrated by the historical evolution of popular sovereignty and ‘rule of the people’ (see esp. Morgan 1988; Urbinati 2012). While goals such as ‘good governance’, the ‘public weal’ or ‘national interest’ can be pursued conceivably in any political system, the
popular dimension of democracy, grounded in the equality of citizens, demands coping and balancing with additional principles. And though different outlines are possible, they can be delineated as follows: congruence, participation, inclusion and representation. These pose ‘problems’, or more precisely tasks and challenges to be met in democracy, and they bear considerable overlap with one another. From them follow the necessities of a congruence or ‘match’ between being affected and having opportunities to be included and participate in political decision making. In modern democracies, in addition to direct channels of participation (e.g. direct democracy, membership in political and civic organization, rights to vote for and even hold public offices, etc.), this goes hand in hand with representation.

Of course representation for its part constitutes a complex matter with likewise various meanings and thus practical implications. In the political context of a democratic system alone, representation can be delineated according to the classic typology of Pitkin (1967) into three basic types: a ‘descriptive’ representation, which refers to a reflection of the composition of a population, so that representatives or a representative body ‘mirror’ in more or less proportion a variety of attributes (e.g. age, gender, ethnicity, ideology or party preferences and so forth); a ‘symbolic’ representation that gives expression of the political order or parts thereof (e.g. through persons like a head of state or figureheads, emblems, ceremonies and so on); or a ‘substantive’ representation referring to acting on behalf of others more or less in a sense of advocacy (for the citizenry as whole, for particular groups, persons, the electoral district, etc.). Tied with the different types of representation are accordingly different representative roles such as agent, delegate or trustee, underlying the various relational aspects of representation (Saward 2014; see also Mansbridge 2011; Rehfeld 2011). Moreover, in representative democracy then, electoral links between citizens and the government not only serve as institutionalization of political equality through universal adult suffrage and the allotment of ‘one person’ with ‘one vote’ (Dahl 1998); they also provide mechanisms for establishing and
maintaining relations of representation as well as responsibility and responsiveness of the representatives to the ‘represented’ as equal citizens (see e.g. Jacob 2015; Urbinati. 2011).

In addition to periodically and fairly held elections themselves, the electoral dimension in representative democracies is embedded in complex and ongoing processes of interaction between politics and society. They occur among politicians and political parties, citizens as individuals and groups, civic organizations and interest associations, as well as media, and involve the continuous formation, articulation and exchange of opinions, ideas and positions. The inclusion and effective participation of citizens can transpire directly, e.g. through voting, petitions, attending town hall meetings and so forth, or mediated through organizations such as parties, civic and interest groups toward multiple channels of representative democratic governments. Finally, the different forms and roles of representation coincide in turn with a variety of concepts of constituency. This can refer in the representative context more specifically to types or groups of ‘represented’, be they constituted for instance by territory (e.g. electoral districts) or by interest and concern, among others (e.g. affected and interested groups) (see e.g. James 2015; Rehfeld 2005). To briefly reiterate, representative democracy rests on fundamental principles and premises of citizenship, while elections and suffrage rights have a central meaning, both for procedural as well as substantive normative reasons. Beyond the mechanics of electoral systems, elections are pivotal features purported and designed so as to foster representative-democratic principles such as self-determination and equality.

On the other hand, it is obvious that democratic practice cannot always uphold its promises. This may be reflected empirically, as has meanwhile been long discussed with a view to overall lower civic participation in many countries or the increase of attitudes of ‘critical’, disaffected or ‘standby citizens’ (see e.g. Amnå 2010; Dalton 2004; Norris 1999; Putnam 2000). Given the ‘reflexivity of democracy’ (Schmalz-Bruns 1995), and in line with concerns not only for adequate representation but also inclusion and participation, there has been an intense expansion of research on enhancing these democratic goods. Propelled by, among other things,
a growing sensitivity for inclusion of marginalized and otherwise underrepresented persons and
groups in heterogeneous societies (Young 2000; see also Offe 1998; O’Flynn 2010), the
spectrum of democratization approaches is broad. It ranges from ‘strong’ participatory
democracy (Barber 2009), associative democracy (Hirst and Bader 2001) or deliberative
democracy (e.g. Fishkin 1991; Habermas 1996; Manin 1985) as paths to including ideally all
affected groups in public decision making, engaging in discourse, debate and argumentation
and thus involvement around ‘voice’ and not just ‘vote’, digital democracy (e.g. Coleman and
Blumler 2009) or the revival of an ‘aleatory’ democracy securing stronger government of the
people by complementing the representative democratic institutions with ones selected by lot
(Buchstein 2010). Such considerations, here comprising a mere slice of participatory
democratic concepts, seek to foster improved political efficacy and empowerment (see e.g. de-
Shalit 2004; Fung 2004; Shapiro 2002). On the whole, we find that the overarching principle
of equality coupled with congruence, inclusion, participation and representation make up
democratic promises. They serve likewise thus as expectations, points of reference and drivers
for problematizing, i.e. identifying ‘problems’, and for improving their realization in practice.

From this perspective, potential problems and deficits of democracy can be detected and
assessed. However, in addition to concerns for equality and its realization in political practice,
it is necessary to differentiate between causes or factors of inequalities, already for analytical
purposes alone but especially because this affects, in turn, how to address or redress them. Not
only, but particularly in the context of disabilities, barriers to inclusion and participation can be
divided into ‘internal’ and ‘external’ (Kohn 2008). Of course, disabilities are not mere medical
‘facts’, but rather context dependent and socially constructed, so that a differentiation between
internal and external factors, at some level, could be deemed overly contrived. This dichotomy
can be applied, with the necessary sensitivity to complexity in mind, still to reduce ambiguity
and provide a useful framework for analysis for pinpointing where factors of exclusion and
marginalization lie and where, if possible, to take remedial approaches.
3. **Challenges of dementia for democracy**

Fundamental democratic challenges and even deficits have emerged on account of the character of dementia as well as its growing incidence and prevalence. All the more astonishing and troubling should be the gaping lack of attention, especially in political science, paid to democratic-related issues connected to dementia. Not only are we hard pressed to find solutions to the respective democratic challenges, it remains necessary to problematize them in the first place, in social science research and in societies in general (Sonnicksen 2016). The scope of relevant issues and challenges is extensive, pertaining to representation, inclusion and participation or conventionally presumed democratic requisites such as legal competence, consent, individual and collective self-determination and autonomy. In general, these matters are interrelated and difficult to realize simultaneously in practice, and become all the more complex with regard to individuals with dementia.

*A brief review of dementia from biomedical and citizen perspectives*

Dementia is associated with a variety of conditions and different meanings, but also some misconceptions. Most forms of dementia, of which Alzheimer is the most common, followed by vascular dementia, frontotemporal dementia and those resulting from other disorders, primarily occur in older age. However, dementia does not solely affect the elderly (Harris, 2004), nor is it a necessary part of aging. Alzheimer and other conditions related to dementia affect cognitive or thinking abilities beyond the rather normal patterns of memory loss for instance that often develop later in life. More specifically, dementia is a syndrome that usually entails a chronic or progressive deterioration in the ability to process thought (WHO, 2010: ICD-10, Sec. V). The onset of dementia tends to be “insidious” (WHO 2010) since initial indications are either difficult to detect or easily mistaken for other disorders (Leifer 2009),
while its development is progressive, yet can be divided into stages (Sperling et al. 2011). At the same time, the range of areas of impairment is quite extensive, affecting for instance memory, orientation, comprehension, calculation, learning and speech (see e.g. Rogan and Lippa 2002; WHO 2010), and thus judgement and decision-making capabilities. Consequently, the progression of dementia leads to radical changes not only in personality but also, by most conventional standards, autonomy. Unfortunately, despite major advancements in understanding its course and causes as well as in therapy for alleviating symptoms (Hampel et al., 2011; Mucke 2009), dementia remains as of yet both incurable and irreversible.

At the same time, dementia represents not only a bio-medical, but also a personal and societal phenomenon. For one, beyond the clinical aspects, individuals themselves face for instance complex issues regarding wellbeing and identity on account of such drastic changes to ways of life (e.g. Beard 2004; Davis 2004; Ryan et al. 2009). Such questions bear of course implications in familial and social relations and roles. For a number of reasons, there are difficult and profound challenges, be they medical, economic, ethical, relational and so forth, to face by the social environment, especially for those closest to individuals with dementia such as relatives, friends and caregivers (Schulz and Martire 2004). Moreover, and with a view to demographic trends at the latest (Alzheimer’s Association 2013; Brayne, Stephan and Matthews 2011; OECD 2015; WHO 2012), dementia raises a host of questions for the society at large. This applies not just on account of healthcare and welfare commitments, but all the more so when taking a citizenship perspective.

The multiple risks of an overly biomedical conception of dementia and affected persons have long been pointed out (see e.g. Downs 2000; Lyman 1989). Such efforts have contributed to making apparent the deeply embedded and pervasive cognitivist biases on capacity and autonomy in general and with regard to dementia in particular. Hence, there has also meanwhile been an increasing shift toward a perspective on personhood, which is warranted on principles of human dignity as much as for empirical reasons which attest to the need for
acknowledgement and awareness of the diversity of individual experiences with dementia as much as on how context factors and perspectives influence them (O’Connor et al. 2007; O’Connor and Purves 2009; Nedlund and Nordh 2015). In addition to more person-centered and personhood perspectives, an explicit focus on citizenship has likewise emerged which emphasizes individuals living with dementia as citizens with individual, social and political needs and rights (Bartlett and O’Connor 2007, 2010; see also Baldwin 2008; Behuniak 2010; O’Connor and Nedlund 2016). And yet, there appears to remain a tremendous gap between the social relevance of dementia and corresponding growth in research on the one hand, and the discussion of dementia and affected citizens in an explicitly democratic context on the other. Finally, it is not least against this backdrop that dementia and democracy warrant an – overdue – exploration of challenges and potentials for their remedy and accommodation.

Challenges for suffrage rights and their exercise

Given the centrality of elections to representative democracy, voting would appear to be an immediately relevant concern. In addition to basic freedoms and civil liberties, the right to vote constitutes the utmost fundamental requisite for democratic participation, while the exercise of this right not only legitimizes, but enables in the first place representative democratic practice. In the context of dementia, questions of representation or rather which representation, become pertinent as well as complicated by the progression or stages of cognitive and neurological impairment. This applies in turn due to most conventional standards of legal competence that are linked to suffrage rights. Thus enter our dilemmas.

Dementia is highly variable, taking different courses for instance across individuals and over time. Keeping the citizenship perspective in mind, it is neither dignified nor empirically justified to treat the disorder and certainly the citizens themselves monolithically. But normatively and practically, we must reflect on the implications of how dementia progresses
for suffrage rights and their exercise. Having dementia certainly would not pose any difficulties for voting in early stages and, depending on the course, not for a long time, if ever at all. When cognitive capacity becomes increasingly impaired up to a full deterioration as with Alzheimer and other severe forms of dementia, the result at some point though is a loss of competence, according to many conventional legal standards, as well as independent decision-making ability. This poses a dilemma, and dilemmas cannot be solved, but rather require choices. For the sake of simplicity, we can be said to face two basic alternatives: one is a consequentialist approach based on the status quo, that is, to uphold the link between suffrage and competence; the other is adaptation, that is, to seek possibilities for adjustments and accommodation. Both types of approaches bear, in turn, far-reaching implications profoundly relevant to basic understandings of democracy.

The link between suffrage and competence is an intensely pertinent and in many ways sensitive issue. Indeed, the notion of cognitive-based competence as requisite for eligibility for voting and even full rights of citizenship in general has a long history in political thought and practice (see e.g. Barclay 2013; Clifford 2014). This coincides with an (over)emphasis on information and autonomy with the voting act and its integrity as indispensable parts of democratic processes (see e.g. Ashworth and Bueno de Mesquita 2014). Thus, there is a deep seated cognitive and ‘ableist’ bias that becomes immediately apparent when reflecting on suffrage rights. This persists not only in political thought claiming a necessity of capacity requisites for democratic participation rights (see e.g. Claasen 2011), but also in a host of electoral laws to this day, which can become external barriers to participation.

With regard to dementia specifically, most democratic countries have not yet introduced legal provisions to regulate a forfeiture of voting rights for citizens with dementia. As of yet, comparative country statistics concerning the rules and extent of any disenfranchisements on grounds of dementia are unfortunately lacking altogether. However, most democracies do have legal provisions to deny or even revoke voting rights to citizens on grounds of incompetence,
cognitive impairment or severe mental illness, which would usually occur on the basis of a judicial decision and placement under guardianship (Kohn, 2008: 35-36 and Massicotte et al. 2004: 18-26; see also Blais et al. 2001; Hemmens et al. 2002; Nash, 2002; Raad et al. 2009; Roy 2003). Regarding dementia, there have also been increasing efforts in some US States to determine at which point impairment of a citizen is sufficiently advanced to be deemed incapable of voting (Appelbaum et al. 2005). In this vein, the American Bar Association for example has provided standard criteria for courts to consult in deciding whether citizens with mental impairments may vote (Scher 2015: 60f.). And there appears to be growing efforts, particularly in psychiatry and neurology, to refine assessments of cognitive impairment in cases of dementia specifically with a view to voting capacity (see e.g. Henderson and Drachman 2002; Bosquet et al. 2010; Irastorza, Carujo and Bañuelos 2011; Karlawish et al. 2004).

Aside from rare exceptions such as Canada and Sweden, disenfranchisement through due process on account of impairments to cognitive capacity is legally possible in most democracies. However, disenfranchisement must invite concern, if not outright critique and opposition for multiple reasons, not least since suffrage represents perhaps the most basic of democratic rights. There are strands of democratic theory, but also in an international legal context such as the UN Convention on the Rights of Persons with Disabilities, that reject disenfranchising citizens on grounds of cognitive impairment (Kohn 2014: 487f.; see also UN CRPD Art. 29). It is indeed dubious as to how competence or cognitive capacity can remain valid grounds for denying suffrage to citizens with dementia at a certain stage or other groups of citizens at all for that matter (see e.g. Barclay 2013; López-Guerra 2012). The outright exclusion and disenfranchisement of citizens with disabilities seem incompatible with a series of democratic principles – again from congruence to equality. It seems that capacity testing ultimately places an undue burden and even ‘double standard’ on citizens with dementia, or any person suspected to have cognitive impairment.
But even if we agree to reject a seemingly obsolete and overly idealistic concept of legal competence, a number of problematic aspects can apply on account of ‘internal’ barriers. They can pertain for instance to interest articulation, political trust, or political will formation and expression. If citizens with AD and other severe forms of dementia maintain the right to vote irrespective of stage of impairment, an independent act of voting will often eventually become unfeasible. At some point the individual will depend on others (e.g. to register, to request an absentee ballot, or at some point even to fill out the ballot). Here ethical as much as practical questions emerge concerning a susceptibility to manipulation by others such as relatives, guardians, and caregivers. Casting a ballot, in good intention or not, for another citizen inevitably poses a possible distortion of her will. No degree of familiarity can ensure knowledge of others would vote in the election at hand (e.g. the persons could change their mind, nor can one know for certain, thanks to ballot secrecy, how they voted in the past). This essential ambiguity applies no less to instances of direct democracy such as referendums. As the case may be, without explicit and systematic reforms on voter assistance (especially in casting the ballot) or even to establish proxy voting, there is a democratic deficit already at present and, due to demographic trends, its exacerbation is imminent. Aside from substitute voting (which occurs, but also to an unknown extent), these democratic challenges emerge, surely at some point, for citizens with dementia, i.e. in mid to advanced stages.

On the whole, there is a severe lack of general systematic proposals on appropriate arrangements for coping with advanced dementia in democracy and the exercise of voting rights. Even where regulations have been made, the democratic normative issues remain nonetheless. A fundamental question is, again, whether dementia should compel a loss of voting rights or not; and if so, then at which point or degree of severity; and if not, which is clearly the more democratic choice, how should the exercise of voting be accommodated and promoted for as long as possible. Consequently, the as of yet unresolved reconciliation of dementia and the electoral dimension of democracy remains to be widely acknowledged and discussed.
Participatory democratic challenges

Participatory and more civil-society oriented approaches to democracy focus on social and political engagement beyond elections and voting. Among other things, they share concern for enhanced inclusion, participation and even empowerment of citizens on the whole or groups, particularly marginalized, underprivileged and underrepresented ones. However, the related democratic theory research likewise shares a nearly utter lack of consideration as of yet for dementia. Thus it is necessary to point out, again if only in short summary, that numerous features of participatory democracy can present fundamental challenges and barriers.

Deliberative democracy for instance is particularly interested in bringing all affected and especially marginalized groups into political decision-making processes. To this end, it emphasizes in particular exchange of arguments and provision of reasons, not just voting, in order to reach decisions. For the inclusion of groups affected by dementia such as relatives, caregivers, and citizens with dementia, at least in earlier stages, deliberative democracy would certainly offer a suitable and even promising supplement to representative democracy (Kim et al. 2010). Deliberative democracy (like most participatory approaches in general) poses few to no external barriers to access the corresponding arena. The high cognitive demands of deliberation represent a major point of concern in democratic-theoretical debate because they could contribute to intensifying inequalities in participation and efficacy (see e.g. Chambers 2003). The focus on verbal communication and argumentation in particular would amount to difficulties for participation, to some extent in early stages but certainly with progression of dementia. Of course, in general the pursuit of public policy through stronger “communicative practice” offers numerous participatory and policy benefits (Fischer and Gottweis 2012). Especially for policy related to dementia, this could entail consultation and participation of affected communities (e.g. families, caregivers, practitioners from related professional fields).
For the citizens with dementia themselves however, deliberative policy-making approaches are not unproblematic and could even contribute further to marginalization of citizens.

While there are substantial cognitive demands of participatory democracy, certainly more so than with voting, other approaches such as digital and ‘liquid’ democracy would no less entail new forms of substantive discrimination and exclusion. Those with higher resources (economic, educational, time, expertise and so forth) already demonstrate a significantly higher rate of participation in conventional forms of democracy across countries. There are ample indications that new forms of participation may exacerbate this inequality further (e.g. Marien, Hooghe and Quintelier 2010; Stolle and Hooghe 2011), a participatory divide that could be widened even further over time for citizens living with dementia. Similar, if not additional constraints would apply to other forms of democratic practice such as aleatory democracy and citizen assemblies. Such democratic innovations can enrich democratic practice with opportunities for inclusion and participation. Again, with respect to dementia, inequalities in external and internal barriers such as participation eligibility and capability raise as of yet unaddressed normative and practical questions of includability. For instance, it must be discussed whether citizens with AD and other forms of dementia can or would be eligible for random selection to citizen assemblies and their deliberative processes, and if so, again clearly the more democratic choice, how could they be adapted to the diversity of needs, interests and capabilities of those included.

The merits of various concepts of democracy are numerous, though not always uncontroversial in democratic theory discourse. In the context of AD and dementia-related conditions, a number of interlinked problems and challenges apply on account of multiple impairments and their progression in particular. For essentially the same reasons and without exploration of adequate adaptations to the challenges of dementia, participatory democratic approaches such digital democracy or ‘open source’ governance, aleatory democracy, deliberative democracy, direct democracy and so forth would appear to pose possible and
additional barriers for inclusion of citizens with dementia, again especially in advanced stages. Of course, it may be possible to revise these models to accommodate accordingly. However, as of yet in political science, these democratic concepts all have received a severe lack of analysis with respect to dementia.

4. Adapting democracy for citizens with dementia

The development of democracy in practice and in democratic theory reveals that democracy entails more than the aggregation of individual interests through the competition for votes in government systems of separation of powers. Accepting the promises of democracy, particularly to the equality of citizens, it follows that democracy also involves transformative processes through inclusion, communication and representation and requires, as the case may be, the adaptation and multiplication of spaces for exchange and participation (Warren 1992). Furthermore, and quite simply, democracy is not only a matter of individual, but also collective self-determination as well as an immanently societal and communal endeavor. On the one hand, democratic theory and political thought as much as practice have demonstrated a biased predisposition toward ability, capacity and autonomy and thus what constitutes citizenship and eligibility for inclusion. On the other hand, it has likewise become apparent that our ways of thinking about democracy need to acknowledge, if not embrace disability as well as vulnerability (Knight 2014). The latter can take a myriad of forms and are just as indicative of the human condition and thus faced by countless citizens.

It is in this democratic spirit that not only present and imminent democratic deficits and impending for citizens with dementia can be assessed, but also reform avenues within established democratic practices as well as possible alternative approaches may be explored. Though by no means an exhaustive list, it seems appropriate and necessary to point out a selection of adequate approaches. This in turn does not imply an argument for one or the other
type of reform, as each of course would pose their own difficulties and potential incompatibilities. Instead, they should provide an impetus for further reflection and discussion on how to address the fundamental challenges raised in the context of dementia and democracy.

Concerning the electoral dimension, primary issues include how to maintain and exercise voting rights and to fulfil the electoral choice of the citizen with dementia as much and long as possible while preventing manipulation and fraud. This requires more systematic approaches to voter assistance such as on how to proceed in cases of ambivalence. Furthermore, instead of disenfranchisement even in late stages of dementia, the possibility of proxy voting could be considered and would require further conceptual development. A source of orientation can be provided by the discussion on substitute or proxy voting for minors by parents (see e.g. Lau 2012; Olsson 2008). While some have argued that such comparisons are offensive (see e.g. Barclay 2013), which may indeed be applicable, it is not entirely so and depends on the perspective. Indeed the point here is that a number of the questions and principles raised for citizens with advanced dementia overlap such as the critique of capacity and mental competence as common requisites for voting and thus the question of how to rectify the violation of equality resulting from the exclusion of a group of citizens from democratic practice. Vicarious voting for citizens with dementia begs of course several different questions, not least regarding who would exercise such surrogate rights. But whether the debates are comparable or not, it is certainly worth exploring in the context of dementia if proxy voting or forms of democratic advance directives are desirable and possible or not.

At the same time, the discussion on democracy with dementia need not be limited to elections and voting. An array of democratic and political theoretical concepts can provide orientation and inspiration for developing alternative additional avenues to democratic representation and inclusion. Associative democracy for instance could offer a valuable frame of reference, not only for ‘expertizing’ the relevant policing-making structures and processes, but also for organizing communities of affected citizens and developing paths to collective self-
determination (see Bader, 2001, 2014), though would of course require elaboration of how to include citizens with dementia directly. With regard to deliberative democracy, while this approach as addressed above may appear at first incompatible with inclusion of citizens with severe dementia, it should not be ruled out as a reform avenue. Indeed a good deal of research deals with the legitimatory and trust-building potential of deliberative ‘minipublics’ (see e.g. Warren and Gastil 2015) and even to address issues of accommodating deliberation and participation for citizens with severe cognitive impairments (see e.g. Weinberg 2007). Such perspectives especially move beyond the stricter focus on verbal argumentation and accentuate other forms of interaction and exchange, ‘collaborative communication’, and even the role of ‘presence’ of individuals with cognitive impairments and their constructive effects on deliberative forums (see especially Clifford 2012; see also e.g. Calder 2015; Kim et al. 2010).

Furthermore, an endeavor toward democratization with dementia can look to already established and progressing discourses arguing for dignity, compassion, and justice for others who are marginalized, voiceless or otherwise excluded. Accordingly, various concepts for realizing forms of representation and participation are conceivable. Substantive representation warrants consideration in this context. Fulfilling this aspect of representation implies enabling constituencies of citizens with dementia, e.g. in a non-territorially based sense and with regard to affected groups. Representation as advocacy may offer an appropriate concept for thinking about how to enhance and ensure political representation for and with citizens with dementia.

In addition to ‘mirroring’ society (descriptive representation), representation can likewise be viewed as processes of making claims, for example, about, for, or toward constituents (Saward 2010). It also involves practices based, not only, but also on surrogate representation, by which citizens are represented even by representatives they did not elect, civil society organisations or the political system as a whole (Mansbridge 2011). Such considerations may be promising points of departure. However, it is necessary to consider more systematically concrete forms and procedures for guaranteeing effective participation, inclusion and representation. For
instance representation can be enhanced through the system of interest mediation, deliberative forums, or special representatives. With regard to interest group and civil society participation, one promising approach would be to establish an obligatory consultation of dementia constituencies (e.g. groups including citizens with dementia as well as relatives, various professional groups) during legislative procedures in relevant policy areas. Additional approaches could involve holding more deliberative forums such as citizen assemblies and public roundtables that bring together dementia constituencies, policy makers and members of the general public. A further possible approach pertains to establishing special representatives for dementia-related issues, for instance modelled after the long-established Nordic institution of the ombudsman. Any one of these approaches could be implemented, individually or together as much as at multiple levels of government. Thus, a veritable multitude of theoretical foundations, whether along the lines of substantive representation, associational organization, (neo)corporatist interest mediation, or trusteeship, to name a few, provide ample points of departure for development in connection with the challenge of democratization with dementia.

Furthermore, social sciences and political science in particular would benefit from interdisciplinary perspectives for reform proposals. In addition to Psychiatry, Neurology, Geriatrics, Nursing and Social Work, the field of Community Psychology could be a particularly fitting area to consult. This sub-discipline of psychology is primarily concerned with psychosocial wellbeing, inclusion, and empowerment, with particular reference to marginalized and underrepresented groups (Cowen 2000; Dalton et al. 2007). Consequently, it bears considerable overlap with several participatory democratic principles and democratic theoretical concepts such as associative and deliberative democracy. Community psychological intervention programs could also provide valuable impulses on how to realize inclusion and participation for citizens with dementia, even at various stages, drawing for instance on participatory programs designed not just for elderly communities but also citizens with
cognitive impairments (see e.g. Baur and Abma 2012; Corrigan 2002; Ollerton and Horsfall 2013; Shura, Siders and Dannefer 2011).

Selection of possible democratization approaches

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<tr>
<td>Electoral democracy (voting)</td>
<td>- Accommodation (e.g. ballot design, voter assistance)</td>
</tr>
<tr>
<td></td>
<td>- Proxy voting</td>
</tr>
<tr>
<td>Deliberative democracy</td>
<td>- Accommodation (e.g. to communication with cognitive impairment)</td>
</tr>
<tr>
<td></td>
<td>- Collaborative communication, proxy deliberation</td>
</tr>
<tr>
<td>Associative democracy</td>
<td>- Organization of cooperative-like dementia communities (affected citizens, relatives, caregivers etc.)</td>
</tr>
<tr>
<td>Vicarious and interest-based representation</td>
<td>- Neo-corporatist interest mediation</td>
</tr>
<tr>
<td></td>
<td>- Surrogate representatives, Ombudspersons</td>
</tr>
<tr>
<td>Community psychology</td>
<td>- Participatory action research programs</td>
</tr>
<tr>
<td></td>
<td>- Specialized interventions for dementia communities</td>
</tr>
</tbody>
</table>

Most importantly, critical as well as creative reflection is necessary, whether in examining and identifying democratic deficits or exploring ‘realist utopias’ (Bourdieu 2000; see also Bader 2001: 61) to address them. For the purpose of ensuring voice and vote to an ever growing group of citizens, these increasingly urgent issues of democracy with dementia finally have to be raised, discussed, and addressed from democratic theoretical perspectives.
5. Conclusion

Democracies as polities and democratic theory are predisposed to critical self-reflection and thus the continuous search for further development. As sophisticated and extensive democratic theoretical research has become, this does not preclude the persistence of research deficits and overlooked problems. In academic discourse on marginalization, exclusion and underrepresentation, senior citizens are not usually included among the affected groups. This may seem unsurprising for a number of reasons. After all, citizens of middle age and upward tend to vote at comparatively high rates and have a disproportionately high substantive representation in public offices. If anything, we find critiques of such circumstances allowing a purportedly disproportionate amount of influence at the cost of younger generations who, on average, are going to be affected by the political decisions of today for much longer periods of time (see e.g. van Parijs 1998). However, it should be safe to say that such considerations do not square with a democratic society, nor a democratic form of government. The primary concern as much as the primary promise of democracy is not to punish those who have and take part, but to include those who do not. Returning to dementia, it should likewise be clear that dementia is not an ‘elderly’, but rather a ‘citizen’ issue, of course with regard to areas of medicine, care and welfare rights, but also democratic participation and representation.

Dementia calls into question a number of democratic norms and notions. These dilemmas are essentially built into representative as well as participatory democratic models. Moreover, AD and other dementia-related conditions, given their progressive nature, pose another fundamental complication to bear in mind, in that normative and practical implications may also have to relate to degrees or stages and not just the condition itself, not to mention allow for flexibility to the heterogeneity of citizens themselves. Finally, precisely because democracy presupposes equality of citizens, it requires inclusion and participation despite any difficult democratic challenges dementia may raise. The implications of dementia in the context of democracy and citizenship as of yet represents a rather marginal research agenda, particularly
in political science. With the promises of democracy in mind, the discussion needs to be carried out by a variety of academic disciplines and, not least, by the wider public. Taking democracy seriously, as political scientists as much as citizens, commits us to deal with these questions and to search for adapting and accommodating representation, inclusion and participation toward democracy with dementia.

References


