Discourses of dementia and decline in the United Kingdom

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Abstract:

The notion of independence is prominent in current strategies to address the social exclusion of people with dementia in the United Kingdom, as part of a broader narrative of 'well-being' in the condition. This article explores the practical implications of applying this notion. It is based on a study of six qualitative interviews with researchers developing a psychosocial intervention in this country. An analysis of their perspectives and experiences presents how the application of this concept aims to promote agency and an active lifestyle in people experiencing cognitive decline. This intervention thus reflects a narrative of stabilization in dementia contrasting with its progressive nature. Two areas of tension emerge from this narrative in the intervention related to 1) the normativity attached to the principle of independence, and 2) the risk of presenting dependency as a choice. In view of these tensions, this article argues that the predominance of the principle of independence risks naturalizing some of the exclusion experienced by people whose dependency prevents them from taking part in this type of intervention. This article then proposes the concept of technologies of

omission *as an analytical category to study societal interventions, strategies and narratives that omit the position of people in situations of dependency, thus prompting reflection on our selective relationship to cognitive decline and ageing in society.*

[Dementia, Exclusion, Technology of omission, United Kingdom]

1. Introduction

Approaches based on notions of autonomy, citizenship and 'living well' in dementia have become increasingly dominant across North America, the United Kingdom, and in international institutions such as the World Health Organization (WHO). The emergence of this approach results from a long process of social change involving national and international organizations and policy makers, dementia advocacy groups and researchers whose inception Patricia McParland and colleagues (2017) trace back to the innovative work of Tom Kitwood (1997). The objective of maintaining autonomy for people with dementia[1] amidst the progression of their condition is increasingly presented as best practice within the policy agenda of important national and international institutions to address the challenges associated with ageing societies and the rising prevalence of dementia around the world (e.g. Department of Health, 2015; World Health Organisation, 2017). For instance, the World Health Organization (WHO) Global action plan on the public response to dementia 2017-2025 lists '[e]mpowerment and engagement of people with dementia and their carers' as the second most important of its seven 'cross-cutting principles', explaining that '[p]eople with dementia, their carers and organizations that represent them should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research of dementia.' (World Health Organization, 2017, p. 5). This description by the WHO presents how the 'living well' discourse and agenda wishes to establish a novel standing of the person with dementia in society through mechanisms of empowerment, a focus on 'remaining strengths and recognizing enduring personhood' (McParland et al., 2017, p. 259) to counter the social exclusion of people with dementia. To this aim, this approach often draws on the idea of citizenship applied to dementia, which has become an important concept in the work of several scholars aiming at

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[1] As to accurately reflect debates and perspectives from the United Kingdom and other English-speaking countries, we use the term 'people with dementia' which is most commonly used by those diagnosed and within public discourses in these countries.

this objective of empowerment (e.g. Bartlett & O'Connor, 2010; Kontos et al., 2017). In this novel narrative, dementia is envisioned not as a time of loss of personhood, functional and cognitive capacities, and decay, but as a time marked by the continuity of agency, previous life choices and lifestyle opportunities enabled by adequate support and assistive technologies (McParland et al., 2017). In rethinking dementia positively, this approach hopes to alleviate parts of the stigma it identifies as resulting from the tragedy narrative (McParland et al., 2017). Ideas of autonomy, self-management and empowerment in dementia have been important dimensions of this novel approach, hoping to restore confidence in the person with dementia and foster its engagement in daily life, therefore encouraging social inclusion, decision-making and an active and healthy lifestyle through self-management.

Interventions and research based on this narrative have multiplied in recent years. Indeed, a wide range of social interventions and research projects aiming at supporting autonomy for people with dementia has developed following the inclusion of citizenship and empowerment in the conceptualization of this condition. Such projects support failing memory, activity planning, mobility and communication among other with the idea to maintain people with dementia away from institutionalization (e.g. Alzheimer's Society, n.d.-a; Moreira, O'donovan, & Howlett, 2014; UK Dementia Research Institute, n.d.). They attempt to interpret these principles, through community-based, non-pharmacological interventions for dementia, for instance in the US (e.g. Kaldy, 2013), and the UK (e.g. GREAT Cognitive Rehbilitation, n.d.; Alzheimer's Society, n.d.-b).

Although its objectives appear positive, the practical application of this narrative and associated interventions to dementia is not without challenge. As McParland and colleagues (2017) or Chris Gilleard and Paul Higgs (2020, p. 120) explain, this reframing of dementia involves important tensions around the actual experience of people further along the trajectory of decline, as well as those most affected by the disabling effects of ageing. It risks overlooking

the circumstances of people whose condition is intensely marked by the effects of infirmity, complex life-limiting impairments and comorbidities that prevent them achieving these objectives. As these authors note, while this narrative may have a positive effect for some people with dementia who are more functional and able, there is a risk that it might further exclude those individuals who cannot meet these rising expectations around cognitive capacity and autonomy.

However, the reach of this critical standpoint problematizing the discourse of 'living well' in dementia has remained limited in the field of dementia research. More specifically, little empirical research has been conducted on the practical challenges resulting from the application of this discourse in novel psychosocial interventions for dementia. This article therefore departs from the identification of this gap in the literature to further explore and document the paradoxical consequences of this current societal attempt to address social exclusion in dementia.

To this end, this article will explore challenges and tensions in the development of a large research project whose objective is to support people to maintain well-being and an independent life after a diagnosis of dementia. This United Kingdom-based project which mobilized over twenty researchers across several universities and countries over a five-year period and received an important national research grant intends to develop an intervention to support the independence of people with dementia in daily life by activating networks of dementia advice workers, relatives, and people with dementia themselves. As material support, this intervention uses a handbook and an online platform providing guidelines to support decision making, social inclusion and an active lifestyle.

This article presents the analysis of semi-structured interviews with six researchers who were involved in the development of this larger project. Among these six researchers, there were two

clinical psychologists, one programme manager, two dementia researchers with a background respectively in psychiatry and in psychology, and one social scientist. Two of them were principal investigators on the project. They were contacted through the intermediary of the project manager and volunteered to take part in the interview. They provided informed consent after having received a detailed information sheet about the objectives and conditions of the research. They were guaranteed anonymity. This research received ethics approval through the University College London Research Ethics Committee. Interviews lasted an average of 45 minutes each and were audio recorded. These interviews aimed to discuss the meaning that researchers attributed to independence in dementia and their understanding of the benefits of empowerment, agency and choice for people with dementia. By asking the researchers about their experience of developing the project and piloting it with participants, these interviews also explored the tensions involved in applying these principles to support learning and progress in a neurodegenerative condition and how they reflect a particular understanding of decline in dementia and old age. Finally, these interviews explored how the researchers conceptualised those who might benefit from this intervention and the criteria they used to select them. The transcripts of these interviews were then analysed using NVivo software, creating broad themes to classify responses that were closely or remotely related to the questions described above following thematic analysis (LeCompte & Schensul, 1999), and creating more specific codes to inductively present the representations involved in constituting responses to these broader questions using principles borrowed from 'grounded theory' (Glaser & Strauss, 1967; Strauss & Corbin, 1998).

As a result of the analysis of these interviews, the tensions discussed show the difficulty of defining independence in dementia, as well as the impact of this priority given to independence on our understanding of dependency in ageing and dementia. This article will also show how maintaining an objective of independence in dementia implicitly leads to the risk of

confounding dependency with agency. Finally, it will problematize how decline is conceived in the project and how people with advanced dementia are considered as a result.

The results of this analysis will hopefully enable us to better understand the tensions involved in current ideas of 'living well' with dementia by grounding them in the practical implementation of actual interventions. As a result, it will enable us to more generally assess the capacity of this dominant narrative to respond to social exclusion through current policies and interventions across Western societies.

2. Researchers' interpretations of the idea of independence in dementia

When researchers working on the intervention speak about *independence* in dementia, how do they understand this concept and its application to dementia? The question seems straightforward; however, we should see that the definition of this idea in the project remains a complex process involving interpretations relying upon disciplinary pre-notions and contextual elements which are inherently cultural. This process explains how a practical intervention with an objective to support independence in dementia emerges as a result of the narrative of 'living well'.

2.1. Defining independence in dementia

It appeared that the project had no unified definition of independence at the start. Answers indicated that researchers on the project had different understandings of the concept of independence. Some of the researchers were sceptical of the application of this concept to dementia specifically due to the excessive individualism that it implicitly translates. Some of the researchers highlighted for instance that notions of 'interindependence' or 'assisted autonomy' are probably more meaningful for people with dementia. There is therefore an initial

recognition by the researchers that using independence as a principle to drive the intervention in dementia is not without tensions.

Meanwhile, it is also interesting to note that the project did not formally analyse or problematize this concept for dementia in its early development. As a researcher pointed out during the interview:

(…) that wasn't part of the work program, so in the original protocol, the original proposal, there was no work package around defining how the word independence was going to be used in people with dementia. *(Interview 1)*

This absence of definition however did not prevent them from developing the intervention. This observation and the set of principles mobilized in the development of the intervention (e.g. agency and activity) seem to indicate that findings from previous research enabled them to elaborate a research proposal. The research team only used independence subsequently as a concept that could encompass the main ideas of the project. Such an observation also explains why the researchers who mentioned the inherently individualistic nature of independence as problematic were not limited by this critique in developing their intervention. It shows how independence was probably adopted by the researchers for its symbolic appeal, while the content of the project was defined through other means. It does not mean that independence is irrelevant to the project, but that the project brought its own interpretation of this term based on other principles.

2.2. Maintaining an agentic self

In this regard, one of the key principles behind the interpretation of independence by researchers is to '[enable] people to make decisions and choices, [enable] agentic choices' as a researcher pointed out in the interview. Accordingly, researchers perceive the ability to make

choices and decisions for oneself as a key objective to achieve for people with dementia, and they envision the intervention as instrumental in supporting this process.

For researchers on the project, the existence of agency principally results from *individual will* on the part of the person with dementia, and mobilization of carers and relatives in supporting agency. The research team explains how agency can potentially be compromised and require an external intervention to be reactivated. For instance, a researcher we interviewed describes how the project intents to re-activate this agency:

> *Decision-making is everyday, if you want to do something, if you want to make up your mind, how you want to do it, decision making. So from there, they say 'oow yes, I decided to go to a park', but they are still making decisions. Yes that's right, so we help them to understand decision-making is not a big decision of doing something, but is everyday routine, so they feel good. I still have made a decision.* (Interview 5)

This extract describes the project's objectives to support people in regaining confidence in their own agency by making them understand that they can still be actors in their own lives even after a diagnosis of dementia. 'Coaching', 'education' and 'empowerment' are central to this process as researchers on the intervention pointed out. For instance, another researcher explained how the intervention is about individual goal setting and coaching so that people with dementia can achieve their objectives [notes from interview 5]. Researchers therefore represent agency as a dormant capacity that needs to be 'enabled' both at an individual level and through social transformations.

Following this logic of coaching, empowerment and education, during one of the interviews a researcher pointed out regarding her perception of the project that taking a self-management approach should have a very empowering effect on people [fieldnotes from interview 1]. Future participants in the intervention will be invited by the researchers to develop a plan of activities

to implement in their daily life. This represents for the researchers a means to maintain this ethos of agency and enterprise in the person with dementia. Indeed, the researcher explains that people take the plan that they have developed as part of the intervention with them and might be able to follow this plan and actually make changes into their lives [fieldnotes from interview 1]. This approach to agency in dementia based on self-management therefore principally relies upon the will of individuals to implement lifestyle transformations, and the intervention is designed as a support to achieve this objective.

Empowerment as a concept used in the health domain is not without critique, and some of these critiques are relevant to understand the implications of this concept applied to dementia. For instance, empowering in health promotion can also mean controlling, as Isabelle Aujoulat and colleagues (2008) explain. Interventions relying on the principle of empowerment are essentially turned toward the objective to encourage patients to control their own condition in order to maintain a separation between their identity and their illness. Such process, Aujoulat and colleagues (2008) emphasize, overlooks the need to 'let go' 'by accepting to relinquish control, so as to integrate illness and illness-driven boundaries as being part of a reconciled self' (2008, p. 1228). Aujoulat and colleagues (2008) argue that the approaches of 'controlling' and 'letting go' are both necessary when attempting to improve the well-being of patients and that one shouldn't be privileged at the expense of the other. Yet, this logic of 'letting go' remains peripheral in the project's conception of 'living well' in dementia and its strategy of empowerment and control of the condition. This approach can lead to tensions as we will see later in the article.

2.3. Maintaining an active self

In the perspective of the researchers we interviewed, mechanisms of empowerment, coaching, and education are not solely implemented for the sake of supporting agency. They also aim at encouraging an *active lifestyle in dementia*. This second important objective constitutes another dimension of the attempt of the project to reframe dementia in a positive light, as an active version of oneself opposed to passivity and inactivity.

This priority given to activity in its physical, cognitive and social dimensions is an important component of the guidelines and topics contained in the handbook and digital app' that the project team developed as the main material support for the intervention. The handbook offers a framework providing structured guidelines for the person with dementia and its relatives helping them to select activities of a physical, cognitive and social nature that they can implement in their lives. It also offers advice and tips to manage the challenges that dementia brings. Researchers expect that this handbook and app', together with the help of relatives and a dementia advice worker will help people with dementia to develop and implement an activity plan thereby creating a schedule of the physical, cognitive and social activities that they will undertake in their daily lives. The researchers we interviewed hope that such activity plan will help the person with dementia to maintain their health, autonomy and well-being as a result. This objective of activity therefore combines with the previous objective of agency to create an integrated whole, a vision of life with dementia where decision-making is directed toward the promotion of an active life and a regime of health relying on principles of self-management.

Hence, the project's objective of empowerment specifically oriented toward the maintenance of an active and healthy lifestyle is inherently *normative*. Outside the field of dementia, the normativity attached to empowerment has been previously documented (e.g. Aujoulat et al., 2008; Cruikshank, 1999; Grace, 1991). This normativity is present in the application of the

strategy of empowerment to later life, carrying a dimension of control as we saw above in the work of Aujoulat and colleagues (2008). When it comes to dementia, empowerment is constitutive of an ethic of life with specific standards to maintain in ageing and dementia. The regular review of the activity plan through meetings with the dementia advice worker and their relatives constitutes an occasion for this norm to be monitored and stabilized through time.

The translation of a narrative of 'living well' into practice can therefore be characterized by this objective of *stabilization* of the condition. This is where tensions emerge, in the apparent paradoxical relationship existing between this objective of *stabilization* emerging from the contextual and scientific development process of the intervention, and the neurodegenerative nature of dementia which often leads to a substantial progressive decline in cognitive functions and capacities necessary to support an autonomous and active life. As we will see in more detail in the next section, through this idea of stabilization of the condition, the project carries a dimension of controlling which can override the other approach of 'letting go' (Aujoulat et al., 2008) and integrating the decline of dementia into one's identity.

3. Tensions implied by a narrative of stabilization in dementia

Indeed, when considering the decline present in most of the cases of dementia, this objective of stabilization can appear antithetical at first sight. Experiences of the researchers with the implementation of the pilot phase of the project based on this approach indicate the presence of practical tensions.

3.1.First tension: autonomy as a norm and the devaluation of dependency

A first tension in the project concerns the risk of conflating *autonomy as a possibility* which should be supported in dementia if the person expresses a preference for it, or welcomes

interventions toward this end, with *autonomy as a normative expectation* maintained by the objective of stabilization in dementia and systematically applied to individuals with the condition. Indeed, the former principle does not expect people to act autonomously while the latter actually implies a value judgement when autonomy is not achieved. This value judgement is not necessarily explicit and direct, but it can be implicit and indirect.

This normative expectation of autonomy in the project is perceptible in one of the interviews. A researcher on the project explains how choice can be a burden for some individuals based on her experience during the exploratory phase of the project.

> *Yeah, yeah, I talked to people and they didn't wanna make a decision. It was too hard. They were happy to be told what to do because actually it was too physically tiring to have all of those thoughts going round in their head. 'Do I want my blue jumper or my red jumper? Etc.' And the wife said [her spouse] was getting so agitated, even when she offered two choices that in the end she just laid his cloths out. And he said I am much better now, I was getting so stressed about whether I made the right choice. So we assume people want to make decisions and choices.* (Interview 6)

In this extract, we see how the experience of the individual ends up contradicting the hierarchy of values established by the project placing autonomy at the top. Individuals living with dementia may not always prefer autonomy over assistance and may find well-being within decisions made by proxy. Dependency can be a means to avoid distress, maintain quality of life and identity as this testimony indicates.

The experience described by the researcher in the interview is relevant to nuance the position taken regarding independence in the project. The researcher herself points out that the expectation that people with dementia wish to make decisions and exercise their agency can be an assumption which is made about them.

3.2.Second tension: the risk of portraying dependency as agency

In assuming that dementia is a stable condition, decline risks being misinterpreted as a choice. Agency therefore risks becoming *a performance* maintained by individuals surrounding the person with dementia, a projection of the expectations of the carer or healthcare professional on the person with dementia.

A pertinent example of this possible confusion can be found in the mechanisms used by carers to facilitate decision-making by the person with dementia. *Option-listing* is one of these mechanisms. This term is used to describe a specific technique of person-centred care where for instance a carer/supporter asks a person with dementia whether she prefers to drink tea, coffee, or orange juice. The technique consists in enumerating the possibilities available to choose from for the person with dementia. This manner of asking a question can appear less distressing and easier to understand for some individuals with dementia than actually asking the open-ended question 'what would you like to drink?' which could lead to confusion due to the large variety of mental pathways that the individual would have to go through (e.g. understanding that we are speaking about drinks, that this is a preference that one should express, recalling previous life events on which this preference is based, etc.). This option-listing technique is a common practice in situations informed by theories of person-centred care.

Let us now consider the response of a researcher on the project to understand the tensions involved in this technique:

From my interviews, for different people they describe different choices. For example, one carer said: 'with my mom, if you give her four choices, none of the choices it's going to be. So for them 3 maybe maximum, or 2. But for some people they want to give more

choices. It is helping them to pick the right choices. That is something you have to

understand what their situation is.   *(Interview 5)*

In this extract, the researcher presents the necessity to narrow down choices based on the cognitive capacities of the person following this technique of option-listing to facilitate the understanding of the person with dementia. Although one could argue that this technique is a key means to support agency and autonomy in dementia, the level of interventionism required from the carer in this process should also be emphasized. From the vast array of choices that the person would have made in a life prior to dementia, there only remains two options available in this example, transferring a substantial part of the agency of the person with dementia to the carer and his/her own biases in selecting possible choices based on assumptions of the person with dementia's preferences. These preferences may be deduced from previous habits if the person applying the technique knows the person with dementia well and is well meaning, but the technique may also be applied within the framework of a professionalized care therefore substantially reducing the chances that the professional carer will know about the preferences of the person. This idea of knowing the preferences of the person from experience prior to the progression of dementia also implies that preferences used as a basis for the constitution of the list are stable attributes. It therefore implies that taste does not evolve across the life course. Overall, and beyond considering whether this strategy of reducing choices by the carer is done by necessity or not, it already represents a process in which decision-making is substituted. We can therefore already question the categorization of this strategy as an example of actual independence or autonomy.

Furthermore, this researcher mentions the idea of a 'right choice' as defined by the carer, supporter, or clinician. This idea of a 'right choice' also interferes with independence due to its interpretative dimension based on the understanding of the carer, supporter, or clinician about the possibilities that should be available to choose from for the person with dementia – the ones

that are 'right' (and implicitly the ones that should be prohibited because they would be 'wrong'). There may therefore be an inevitable drive for the carer/supporter to propose only the possibilities to choose from that they deem appropriate.

To this regard, Toerien and colleagues (2018) explain how 'option-listing' can generate the illusion of choice while implicitly directing the person toward the preference of the carer or the healthcare professional – healthy food or activity for instance – even if they contradict prior preferences of the person with dementia. Independence risks becoming an illusion rather than actually being based on the exercise of agency. This illusion potentially hides the challenges that dementia imposes on autonomy in public narratives and discussions. Hence, qualifying this practice as an example of autonomy could therefore overlook a discussion of how dementia itself can impair independence and the ideal of person-centred care.

The argument here is not about rejecting the practice of 'option-listing' altogether, as it can be an adequate means to enable a certain level of choice in advanced dementia for instance. However, there can be an illusory nature to choice which is obscured by ideal representations of autonomy.

Other examples of this reframing of the impairment of dementia as an expression of agency and autonomy can be traced in the project. For instance, some advice for people with dementia written in the handbook supporting the intervention states the following:

'*[d]oing less of something because you are having trouble with it, or need more support with it? Doing less, or stopping doing something is okay as long as it's a positive choice for you*'.

In this extract, interrupting an activity is presented as an outcome of choice, of the person with dementia exercising agency. Through this approach the experience of decline in dementia can potentially be reframed as a positive choice rather than a loss of the ability to continue doing what one previously enjoyed. This constant emphasis on choice therefore risks not recognizing

loss and impairment or impeding discussions of decline when it is part of a broader strategy reframing dementia in a positive light.

The use of the idea of compensation by one of the researchers interviewed implies similar concerns in potentially impeding discussions of decline. Following our question '[h]ow does the manual respond to the decline that comes with dementia?' the researcher responded the following:

> *The manual gives some foundation through the information. It encourages them to search for new activity. So as the dementia is progressing, it is to the person to adapt some of the activities that they can still do. To come back to my theory, they compensate. (…) we have to encourage them to look at their strength.* (Interview 5)

Just like the reframing of loss as choice, the promotion of compensation for the person with dementia to address their own decline similarly tends to hide the presence of decline behind a reference to decision-making. Compensation, and by extension self-management as referred earlier by a researcher appear compatible with values of autonomy and self-definition yet become less applicable to individuals in the later stages of dementia and risk generating pressures on the person to maintain autonomy which may obstruct possibilities to discuss experiences of decline for the person with dementia. One may ask therefore to what extend this expectation of compensation can prevent people with dementia from voicing their struggle with decline.

We can draw a parallel between the tensions between agency and decline, and the important questions Anne Basting (2001) raised in her previous work on storytelling in dementia. Basting (2001) set up a play based on storytelling workshops she conducted with people with dementia. While the play was a success overall in displaying a positive image of dementia to the public, Basting (2001) pointed out her understanding that it may be hard for people directly engaged

with dementia to find meaning in this positive vision of the disease, while enduring the daily challenges of a caregiving role and the decline of a loved one. Such difficulty inevitably transpires in the intervention studied in this article, and the more general context emphasising the idea of 'living well' with dementia. It risks neglecting the issue of suffering and loss in dementia. While the image of a positive dementia may work for the time of a play, it can be more challenging to conceive it as a long-lasting objective to implement for a whole intervention as it is exemplified in this section mentioning the risk that independence becomes performative and illusory as the dementia progresses.

4. Tensions challenging the concept of 'living well' in dementia

These previous sections showed the presence of tensions in practical applications based on the abstract narrative of 'living well' in dementia, and how they gave priority to individuals in early-to-moderate stages of the condition. We should now use these tensions to more critically assess the principal ideas composing this narrative and the nature of social exclusion associated with it.

This intervention indicates how practical applications of the narrative of 'living well' in dementia give central stage to encouraging agency and decision making. An important ramification of the 'living well' discourse has generated important claims for the virtue of a *citizenship approach* in dementia (Bartlett, 2016; Kontos et al., 2017; Yates et al., 2019, p. 1616). Ideas of empowerment described in the interviews above closely follow novel citizenship approaches to dementia (Bartlett & O'Connor, 2007, 2010). Indeed, these approaches give similar importance to notions of empowerment and the centrality of individual agency in implementing changes in daily life, only impaired by negative power relations imposed by people's social environment. As Pia Kontos and colleagues (2017, p. 183) explain

regarding what they call 'relational citizenship', this is 'a model that stands to advance the discourse on citizenship by offering an important rethinking of notions of selfhood, entitlement, and reciprocity, which are central to a sociology of dementia'. By introducing 'relational citizenship', these authors expanded the approach beyond the realm of relations of care previously advocated by Kitwood (1997) in order to frame the inclusion of persons with dementia as a matter of citizenship and highlight the oppression of people with dementia by society and their existence as a marginalized group (Bartlett & O'Connor, 2007).

However, the first tension presented in this article described how researchers had to deal with the fact that independence may not always be desired by the person with dementia because it is simply distressing. By extension, living independently may not always be feasible for the person with dementia due to the extent of its impairment. Hence, if we look at citizenship in dementia through a lens acknowledging this tension, we should question whether individuals always wish to engage with their dementia through this lens of independence and citizenship. Is this dimension of citizenship not creating novel norms around dementia which may not always be attainable, and could therefore become exclusionary for some?

By reviewing the strategy of option-listing, the second tension presented in this article explored how there is a risk for the promotion of agency to not recognize the implicit directiveness of these strategies and subsequently overlook the existence of decline and impairment. Hence, we should ask whether a citizenship approach does not carry a similar risk of unconscious directiveness and non-recognition of decline for a part of the people with dementia? Just as there is a risk of bias in the idea of the 'right choice' for people with dementia, there is also a risk of bias toward the 'right citizenship' for individuals with the condition. Gilleard and Higgs (2010) previously characterized the agency of individuals encompassed by the social imaginary of the fourth age in relations of care as a 'hyper-reality', making choice a projection of the preferences of the carers and staff. Similarly, this risk of projection should be raised in applying

citizenship in dementia as it can misrepresent the needs of those beyond the mild stages of the condition who may not have expressed these claims toward citizenship themselves.

Calls for activity and agency implied by independence in dementia are inevitably connected to an idea of stabilization. In a neurodegenerative condition, stabilization implicitly requires prevention to remain sustainable. This promotion of activity, stability and prevention is an important aspect of the approach of community-based social interventions for dementia more generally (Burgener et al., 2009). When placing dementia into the broader context of ageing, one can see how approaches based on stability and prevention of cognitive and physical decline relate to the objectives of *active (cognitive) ageing*. The narrative of 'living well' in dementia strongly echoes the principles developed by this ideal dominating current ideological approaches to ageing and health across Western countries and beyond (Gilleard & Higgs, 2010; Lamb, 2017). The allusion to prevention in 'living well' discourses remains a fundamental tension due to its antagonistic relationship with decline in the absence of evidence supporting prevention strategies for dementia. This discomfort with decline is shared with active ageing more generally.

5. Conclusion - technologies of omission naturalizing social exclusion

As we deduce from this analysis, the most important shortcoming of current strategies relying on the discourse of 'living well' in dementia, including those based on the novel idea of citizenship in dementia, is their inherent *omission* of decline, and the individuals which are most affected by it, those with more advanced dementia. This article therefore proposes to categorize strategies and interventions of 'living well' in dementia, those who attempt to stabilize dementia through the promotion of agency, activity and prevention, as *technologies of omission.*

Inspired by Foucault's (1988) concept of "technologies of the self", technologies of omission play a passive role in exclusion by neglecting the condition of those individuals with advanced dementia who are only secondary beneficiaries of this type of intervention. While it may have limited effects when being promoted in a single intervention like the one presented in this article, the sheer dominance of this narrative in current dementia strategies becomes more concerning. Indeed, technologies of omission accept, or even naturalize the social exclusion of the most vulnerable and dependent individuals with dementia. This exclusion is presented as being unavoidable. As this article illustrates, technologies of omission are limited in their ability to support individuals as they progress along the trajectory of decline in dementia.

Technologies of omission therefore have a capacity to generate *otherness*. They prevent us from properly assessing the needs of those whose condition is a barrier to the use of these interventions. Sharron Kaufman (1994), George Agich (1990) or Eva Feder Kittay (2011) already considered this issue with regard to impairment in care for instance. As Kaufman (1994, p. 47) emphasizes, citing the position of Agich (1990), "[i]n a recent assessment of autonomy in long-term care, George Agich notes how abstract ideals of autonomy are counterproductive and that an adversarial approach to independence/dependence prevents us, as a society, from developing adequate models of care and choice". Kittay (2011, p. 55) also problematized the use of autonomy as a norm in care in the negative impact that it has by disregarding any dependency as problematic. Independence becomes a pressure due to its normative nature. It can hinder our ability to assess and address decline, and obscure our ability to make it an object of reflection that can be manipulated as part of societal discussions. To this regard, Haim Hazan (2011, pp. 13–14) points out that 'seductively obscure terms such as empowerment, resistance, resilience, gerotranscendence, and spirituality have been amply employed in recent gerontological discourse to serve as a vocabulary in the moral economy of aging (Minkler & Estes, 1991), thus absolving society from practical accountability and

responsibility for the unsettling category of the socially disenfranchised'. The multiplication of this type of intervention can result in the naturalization of the social exclusion of people with dementia, portraying their condition as inevitable. Technologies of omission prevent us from asking more complex questions around the corporeality of decline, care, and life in the most advanced stages of the condition. These questions should be addressed to palliate this exclusion.

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