Active inclusion of people living with dementia in planning for dementia care and services in Low- and Middle-Income Countries

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Abstract

Involving people living with dementia in service design and planning has become more common in high-income countries. It remains rare in low- and middle-income countries where two-thirds of the world's people with dementia live. In this commentary paper, we explore the barriers to inclusion of people living with dementia in planning in low- and middle-income countries and make a case for the inclusion of people living with dementia in care and service planning. We suggest how this can be done at individual, community or national and state level using the following principles: 1) respecting the rights of people living with dementia to self-determination; 2) valuing people living with dementia's unique understanding of dementia; 3) creating a culture of active inclusion which creates a space for people living with dementia to participate; and 4) ensuring appropriate accommodations are in place to maximise participation.

Background

Ensuring dementia care services are designed *by*, rather than simply *for*, people living with dementia is being increasingly supported by both service users and producers. The drive to involve dementia service users in service design and planning has become more common in high-income countries (HICs) (Hanson et al., 2007; Leorin, Stella, Nugent, Cleland, & Paggetti, 2019; Lorentzon & Bryan, 2007; McIntyre, 2003; Penrod et al., 2007; Read, Toye, & Wynaden, 2020). However, it is rare in low- and middle-income countries (LMICs), where two-thirds of the world's people with dementia live (Prince, 2015). Adequate and appropriate inclusion of people living with dementia in service development respects their right to autonomy and self-determination (making decisions which affect the self) (Kornfeld-Matte, 2015), helps to address unequal power dynamics between service producers (e.g. policy makers, medical practitioners) and users (Lorentzon & Bryan, 2007), and may ultimately result in more accessible, effective and relevant services (Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013). For those directly involved in the planning process, adequate inclusion is expected to help reduce stigmatising behaviours among health and policy practitioners (Abayneh et al., 2017; Gupta & Roberts, 2014) and encourage those with dementia to feel more empowered (Gupta & Roberts, 2014; Hagan & Campbell, 2021) and respected (Whitfield & Wismer, 2006).

Planning for dementia care and services in many LMICs has been limited by other health priorities and constrained resources (Jamison et al., 2018). Nevertheless, the World Health Organisation's Global Action Plan on the Public Health Response to Dementia 2017-2025, which was adopted at the World Health Assembly in 2017 (World Health Organization, 2017) documents the commitment of LMIC to producing multisectoral National Dementia Plans. Most of these are yet to be developed: by the end of 2020, only six middle-income countries and no low-income countries had published Plans (Alzheimer's Disease International, 2019).

In this commentary paper, we make a case for the inclusion of people living with dementia in developing and operationalising National Dementia Plans in LMICs and provide some specific suggestions for how to achieve this. Although there is little documented on this topic, there have been substantive policy successes in LMICs by people with lived experience of disability. For example, in South Africa, the disability rights movement was instrumental in influencing the South African

Constitution in 1994 (Howell, Chalklen, & Alberts, 2006) and people living with HIV were instrumental in advocating for change in access to antiretrovirals for treatment of HIV (Heywood, 2009). The principles which we suggest and operationalise in this paper are based on inclusion research in other areas, such as mental illness, and from lessons learned with regards to dementia in HICs. We also draw on our experiences as people living with dementia (MB, KS, ET), care partners of people living with dementia (IG, MP, DT), members of dementia advocacy organisations SA, EB, ACH, EF, IG, MLO, CM, DO, TPS,KS, MS), service providers for people living with dementia (SA, IG, DO), researchers working in the field of dementia, long-term care, and planning for services (SA, EB, ACH, EF, IG, MLO, CM, DO, TPS,KS, MS), and people with experience of living and working in LMICs (SA, EB, EF, IG, MLO, DO,MP, TPS, MS). Finally, we draw on recent experiences of including people living with dementia in the planning and development of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project (https://stride-dementia.org/) in Brazil, India, Indonesia, Jamaica, Kenya, Mexico and South Africa (E Breuer, Comas-Herrera, Docrat, Freeman, & Schneider, 2019).

While we recognise the vast heterogeneity of LMICs, we also observe that challenges and solutions associated with including people living with dementia may cut across contexts, including HICs. We also recognise that most of the literature referred to in this commentary paper represents urban rather than rural centres.

1. Barriers to participation of people living with dementia

Research on mental health has demonstrated that people with lived experience can contribute to service planning at different levels (Tambuyzer, Pieters, & Van Audenhove, 2014). For individuals, assuming or contributing to decision-making about one's own care is crucial. At the community level, contributions could include the planning and development of local services, advocacy, guideline development, monitoring and evaluation and research governance. At the state and national levels, participation could range from policy discussions to national level planning of services. However, substantial barriers to inclusion of people living with dementia in LMIC exist at each of these levels.

1.1 Barriers to individuals' involvement in care decision-making

Individuals' ability to assume or contribute to decision-making about their care is limited by both late diagnosis and limited opportunity.

Dementia symptoms are often understood to be expected consequences of ageing, (Oliveira et al., 2021) leaving dementia underdiagnosed or diagnosed late. Delayed diagnosis is particularly pronounced in LMICs where families and health and care practitioners are less likely to be aware of dementia or to have received dementia training (Juárez-Cedillo, Jarillo-Soto, & Rosas-Carrasco, 2014). In Brazil for example, it's estimated that only around 23% of people living with dementia are diagnosed (Nakamura, Opaleye, Tani, & Ferri, 2015); in India, that figure is estimated to be less than 10% (Dias & Patel, 2009). Individuals experiencing more advanced dementia symptoms are more likely to lack capacity to communicate their needs or make informed choices about their care. In Mexico, evidence suggests that when it happens, dementia diagnosis is frequently late, when cognitive decline and functional impairment is marked (Juárez-Cedillo et al., 2014).

When dementia is diagnosed, it may not be disclosed (Oliveira et al., 2021). Concerns for people living with dementia may motivate practitioners and families to shield them from difficult information and decisions rather than facilitating their right to autonomy and self-determination (Lepore, Shuman, Wiener, & Gould, 2017). For example, in Brazil only 44.8% physicians regularly inform a person living with dementia of their diagnosis (Raicher, Shimizu, Takahashi, Nitrini, & Caramelli, 2008) and only 58% of caregivers endorse disclosing the diagnosis (Shimizu, Raicher, Takahashi, Caramelli, & Nitrini, 2008). In Brazil, as elsewhere (for example, Indonesia, India, Jamaica, Kenya and Mexico), both dominant social norms and laws require adult children to care for vulnerable adults, such as older adults with dementia (Federal Government of Brazil, 2003; Government of India, 2007; Government of Jamaica, 2005; Government of the Republic of Kenya, 2018; Republic of Indonesia, 1971). In doing so, adult children may assume responsibility for medical and financial decisions relating to dementia care (Kristanti et al., 2018).

Structural inequities can also act to limit individuals' involvement in care decisions. For example, literacy, economic and social disadvantage can limit participation (Janic, Kimani, Olembo, & Dimaras, 2020), as can the design of care systems, including healthcare environments and the adequacy of disability supports (Whitfield & Wismer, 2006).

1.2 Barriers to individuals' involvement in community-level care planning

In many LMICs, dementia is stigmatised (Alzheimer's Disease International, 2019). This stigma is likely to arise within institutionally-based (health service and policy) and community-based social relations, shaping how healthcare practitioners, policy makers and planners respond to and value the voices of people living with dementia (Abayneh et al., 2017) and the willingness of people living with dementia to disclose their diagnosis and risk social exclusion (Alzheimer's Disease International, 2019). Our qualitative research with people living with dementia and their families in Brazil indicates that stigma also manifests in questioning the views and experiences of people living with dementia, leading to people living with dementia internalising this doubt (Oliveira et al., 2021). In the absence of supportive intervention, such people are less likely to volunteer to participate in community-level care planning.

While increasing, organisations which explicitly provide a voice for people living with dementia are not operational in all LMICs. Membership of Dementia Alliance International (DAI), an international organisation of people living with dementia, currently has members in 49 countries, although the majority are HICs (Dementia Alliance International, 2019). Other dementia organisations are often run by caregivers or health practitioner volunteers. Alzheimer's Disease International (ADI) is an international federation of dementia associations with partner organisations in 45 LMICs; organisations in 17 LMICs are enrolled in its development programme (L. Dabas, personal communication, 14th August 2020). However, while important in advocating *on behalf of* persons living with dementia, such organisations do not necessarily include them in developing their advocacy efforts, and service provision is primarily designed to support care givers.

1.3 Barriers to individuals' involvement in state- or national-level care planning

As the involvement of people living with dementia in care planning at state/national level is shaped by the barriers to involvement in individual and community level planning, it can be difficult to identify people who have been diagnosed and still have the capacity to communicate their needs to participate or whose families support them to participate. In addition, stigmatisation of dementia may also arise among people working at these higher planning levels. This, along with limited support for people living with cognitive disabilities in LMICs (World Health Organisation, 2019), may lead to the underestimation of the capacity of persons with dementia to contribute meaningfully (Swaffer, 2014).

Participation of people living with dementia in state/national level care planning is made more difficult because in most LMICs dementia care is fragmented. In addition, comprehensive multidisciplinary and multisectoral dementia care policies or programs that include diagnosis and support/treatment are rare (Alzheimer's Disease International, 2019). In most settings, the majority of dementia care is provided by families, other informal paid or unpaid providers, and the private sector (Prince, 2004). Until more recently, dementia care planning has not been a priority in the face of other significant and urgent needs for health and social services at the population level (e.g. high levels of infectious disease, maternal and infant mortality, non-communicable diseases, and violence) (Jamison et al., 2018).

When dementia care and services are being planned, dementia-specific structures or processes to encourage participation may not exist. For example, in Brazil 'social control' systems for eliciting public contributions to health policy and planning are well-established (Noronha & Castro, 2019); municipal, state and national Councils of Older Persons facilitate older adults' contributions (Veras & Oliveira, 2018). However, none of these are dementia-specific or routinely include mechanisms to support participation of people living with dementia or other people with mental disabilities.

2. Pathways to the inclusion of people living with dementia

We recommend that the inclusion of people living with dementia in care planning should be guided by the following key principles, at individual, community, or national and state level:

1. Respecting the rights of people living with dementia to self-determination
2. Valuing people living with dementia's unique understanding of dementia
3. Creating a culture of active inclusion which creates a space for people living with dementia to participate
4. Ensuring appropriate accommodations are in place to maximise participation

These principles are not unique to people living with dementia and can be relevant to other disabilities. However, we show how they can be applied specifically to people living with dementia. At the individual level, we anticipate that they will primarily be used by care providers. These include social and healthcare providers of both formal and unpaid care. At the community level, the principles can be applied dementia organisations, people planning local health and social care services, and those conducting research with people living withresearching dementia. At the state/national level, the principles are likely to be applied by policy makers and planners.
More detail of practical ways to implement these principles are provided as follows below and in Table 1.

Table 1 Strategies to ensure active inclusion

Principles	Individual	Community	State/national
Right to self determination	- Provide person centred care which involves people with dementia in decision making about their care (Lorentzon & Bryan, 2007) - Promote human rights protection (Abayneh et al., 2020) - Disclose dementia diagnosis to the person living with dementia	- Establish and strengthen dementia organisations for people with lived experience (Abayneh et al., 2017; Abayneh et al., 2020) - Build capacity of, and empower, people living with dementia who would like to work as advocates (Abayneh et al., 2017) (Abayneh et al., 2020) - Create roles for people living with dementia in local service development and other committees (Lewis et al., 2008) (Abayneh et al., 2017) - Elicit and respect the person with dementia's decision about disclosing their diagnosis	- Create roles for people living with dementia on planning committees (Lewis et al., 2008) - Create clear guidance with respect to involvement and establish roles and responsibilities (Hickey & Kipping, 1998; Lewis et al., 2008) -
Valuing people living with dementia as experts	- Develop shared care plans and allow the person with dementia to influence decisions (Daly, Bunn, & Goodman, 2018), within both formal and informal contexts of care.	- Develop other stakeholders' knowledge about dementia and decrease stigma (Abayneh et al., 2017; Taylor & Taylor, 2018) - Actively encourage dementia people living with dementia to participate - Ensure people living with dementia are able to influence decisions (Taylor & Taylor, 2020) - Include more than one person with dementia: people with different	- Develop other stakeholders' knowledge about dementia and decrease stigma (Abayneh et al., 2017; Taylor & Taylor, 2020) - Actively encourage people living with dementia to participate - Appropriate acknowledgement of contribution (including financial) (Gupta & Roberts, 2014) - Include more than one person with dementia: people with different types of dementia and at different stages of the disease

		types of dementia and at different stages of the disease	- Include funding in budget (for time and disability support as well as travel and accommodation) - Ensure people living with dementia able to influence decisions (Taylor & Taylor, 2020)
Culture of active inclusion	Establish groups for people living with dementia (Abayneh et al., 2020)	- Encourage person with dementia to speak for themselves (Goeman et al., 2019; Taylor & Taylor, 2020) - Active and respectful listening (Taylor & Taylor, 2020) - Use dementia inclusive language (Swaffer, 2014)	- Respect the person with dementia's choice about whether they wish to disclose diagnosis - Use dementia inclusive language (Swaffer, 2014) -
Ensuring appropriate accommodations	Use practical strategies outlined in Table 2 depending on the needs or preferences of the person living with dementia	Use practical strategies outlined in Table 2 depending on the needs of the person(s) living with dementia	Use practical strategies outlined in Table 2 depending on the needs of the person(s) living with dementia

2.1 Facilitating individuals' involvement in care decision-making

Both structural (e.g. extent, nature and functioning of health systems; stigmatisation of dementia) and local (e.g. family level) changes are necessary to facilitate the rights of people living with dementia to decide on their own care. Some changes are significant and will require a wide-ranging redesign; others could be achieved with more bounded interventions.

For example, introducing shared care plans at a service level may first require steps to both, decrease stigmatisation of dementia among family members and care practitioners, and shift understandings of the often hierarchical 'patient' and care practitioner roles more broadly, to ensure that these gatekeepers value the voice of the person living with dementia in determining their own care pathway. However, it some settings, it would also require the implementation of a clearer care pathway to dementia care (e.g. from primary care to specialist dementia care) in which to introduce shared care plans. In Mexico for instance, there is no unique first point of contact in the healthcare system; no specific sector or 'level' that provides dementia care. Here, the implementation of shared care plans would first require identification (training and awareness-raising) of the appropriate 'service level' such as general practitioners, social workers, and gerontologists.

On the other hand, introducing shared care plans at a family level – where the vast majority of care is provided – may be more straightforward to operationalise. While formal publicly funded strategies are designed and implemented, accessible information and training about dementia, its possible progression and options for non-pharmacological management could help unpaid, frequently family, caregivers to become care partners. This, alongside wider anti-stigma interventions, would help families and others to be as prepared as possible to care for the person living with dementia, and plan care pathways *with them* in a way that takes their needs and preferences into account.

Timely diagnosis of dementia, and disclosure of the diagnosis to the person living with dementia, is a key precursor to facilitating shared care planning at both levels. Increasing public awareness of dementia symptoms and their distinction from 'normal ageing', as well as steps to reduce the stigmatisation of dementia through community based initiatives (Phillipson et al., 2019), could facilitate timely diagnosis by encouraging people with early signs of cognitive impairment and their family members to recognise these signs and seek professional help.

Once a dementia diagnosis has been received and accepted by the person living with dementia, it is possible to contribute developing shared care plans (Daly, Bunn et al. 2018). Our ongoing research and care consultations in Jamaica, indicates the need for gentle and gradual building of a partnership care models over time, in order to counter resistance of those believed to have dementia to seek healthcare or accept the possibility of a dementia diagnosis. Establishing peer support groups for people living with dementia may additionally support this by increasing social inclusion and reducing isolation (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016).

2.2 Facilitating individuals' involvement in community level care planning

Establishing or strengthening advocacy organisations which are led by and for people with dementia could be key to facilitating involvement in community-level care planning (Lempp et al., 2018). These organisations help build capacity and support people living with dementia who are willing to work as advocates, and can help service planners and researchers to identify people living with dementia who are willing and able to contribute to service planning (McConnell et al., 2018). This is important because only a subset of people living with dementia may want to contribute to dementia services and planning, particularly in public fora and in the contexts where dementia is highly stigmatised. For example, despite our best efforts, we were only able to involve people living with dementia in five of seven of our national level STRiDE research planning workshops(Erica Breuer et al., 2021). These consultative workshops included various stakeholders and asked them to map out what needed to be in place to improve dementia care and services in each of the STRiDE countries(Erica Breuer et al., 2021). In Mexico and Indonesia, we invited participation of people living with dementia identified through Alzheimer's associations and physicians providing specialised dementia care but could not find anyone willing to participate. Reasons for not participating included feeling shame about dementia or fear of disclosure, not feeling able to contribute or family members not wanting to put the person living with dementia under excessive stress.

In planning processes, a role needs to be created for people living with dementia to participate in local service development and other committees (Lewis et al., 2008). This includes ensuring people living with dementia are aware of the planning processes and ways in which they can participate. In the service development process, there should be a culture of inclusion so that people living with dementia are encouraged to speak for themselves, are actively and respectfully listened to and are able to influence decisions (Whitfield & Wismer, 2006). To ensure a culture of inclusion, explicit strategies might be required such as increasing stakeholders' knowledge of dementia, decreasing stigma, and changing the ways of working such as using disability supports (Table 2).

While facilitating the inclusion of multiple people living with dementia in any given planning process will obviously lead to better and more informed outputs, having more than one person living with dementia involved may additionally provide peer support and encouragement that would increase the ability of each person to participate and thus strengthen the quality of individual contributions. People living with dementia should be able to participate in community-level planning processes anonymously or without disclosing their diagnosis. This worked well in our research planning workshop in Jamaica where participants were introduced by name but not role, leaving those with dementia to disclose their diagnosis if and when they wanted to. As the workshop progressed, one participant who was initially reluctant to disclose felt empowered to share her own experience and has since shared her experience in another community-level dementia-related forum.

1.3 Facilitating individuals' involvement in state- or national-level care planning

Planning processes, particularly at state/national levels, should have clear strategic pathways for including people living with dementia (Lewis et al., 2008). This should include guidance for establishing their roles and responsibilities (Hickey & Kipping, 1998; Lewis et al., 2008) and doing so in a manner that facilitates their involvement as the disease progresses, including providing disability support (Swaffer, 2014). People living with dementia should be appropriately acknowledged for their contribution including through payment – especially if other experts are paid (Gupta & Roberts, 2014).

Given the shared experience of some elements of living with dementia, where it is not possible to find someone local to include in state/national level planning processes, for example because of fear or stigma, experience from DAI has shown that it may be helpful to initially invite a person living with dementia from another setting to participate. DAI found that the inclusion of people living with dementia as invited keynote speakers or delegates at conferences or participants in focus groups for research, gives courage to those with dementia who have not had a voice to come forward to advocate for themselves.

2.4 Access to disability supports

At all three levels of care planning, people living with dementia should have access to disability supports related to their individual needs. These supports, highlighted in Table 2, include assistance with communication, rehabilitation, physical environments, mental well-being, carers and continued engagement. These are based on literature, our experience with STRiDE and working with people living with dementia. Budgets for planning processes should include these disability supports.

Table 2 Disability supports which can be adapted for individual needs

Needs	Disability supports
Communication	- Prepare and share materials prior to the meeting - Materials should be in plain language, simple to understand and visually appealing with large font sizes (Northway, Howarth, & Evans, 2015) (Goeman et al., 2019) - Pay attention and adapt materials to literacy and health literacy - Arrange a practice/orientation session and follow up session for person living with dementia for important meetings - Have clear and simply communicated tasks and items on which decisions need to be made - Use clear language and avoid jargon (Abayneh et al., 2017; Lorentzon & Bryan, 2007) - Consider shorter but more frequent meetings - Ensure questions can be asked throughout - Check for understanding - Make allowance for 'wrong' ideas and words (Lorentzon & Bryan, 2007) - Use specific communication tools designed for people living with dementia (Wang, Marradi, Albayrak, & Van Der Cammen, 2019)

Physical environment	- Ensure physically accessible location for persons with mobility restrictions - Ensure safe travel to venue available (and reimburse for travel) (Goeman et al., 2019) - Consider number of people in the room(Wang et al., 2019) - Keep noise levels down (Wang et al., 2019) - Ensure clear signage - Have a practice session for virtual meeting platforms with person with dementia
Mental well-being	- Ensure the person with dementia is comfortable (Lorentzon & Bryan, 2007) - Assign a psychologist or support person to the person living with dementia to monitor the needs, provide one on one support and answer questions for clarification
Caregiver or care partner	- Provide funding for a caregiver or care partner to travel with the person living with dementia - Allow opportunities to contribute without caregiver or care partner
Continued engagement	- Create a plan for continued engagement which takes into account disease progression (Whitfield & Wismer, 2006) - Be flexible with alternative options for engagement (e.g. via phone call, individual meeting) and reschedule if necessary

Conclusion

In this commentary, we have presented some challenges related to the active inclusion of people living with dementia in planning for services in LMIC and provided a set of principles and concrete strategies to guide inclusion. We recognise that not all strategies may be feasible to implement or necessary in every LMIC. Structural barriers to inclusion such as the political context, stigma and health systems need to be addressed. Meaningful inclusion is a long-term investment and requires sincere engagement from all stakeholders involved.

Keywords

Dementia, planning, low- and middle-income countries, inclusion, patient involvement

Declaration of Interest

The authors declare no competing interests.

Funding

This work was supported by the UK Research and Innovation’s Global Challenges Research Fund (ES/P010938/1)

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