



Promoting Good Living and Social Health in Dementia

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Abstract The notion of good living in chronic disease in general and, in the case of dementia specifically, highlights the role of social health in preserving the well-being of the people involved. In ageing ageism, discrimination toward older adults is considered an important barrier against involvement in society. In the case of dementia, stigmatisation can have an impact on the person affected, on the family, on healthcare services, and on society more widely. Examples of the impact of discrimination are related to diagnosis disclosure, advance care planning, and the involvement of people with dementia in decision-making about their future treatment. Furthermore, the labelling of the behaviour of people with dementia as a disorder is a way to pathologise it and does not take into account the role of relationships and the social context as a drive for the behaviour itself. As a result of the stigmatisation and the labelling, people with dementia experience epistemic injustice as they are considered neither partners in the decision-making process nor full members of

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society. A capability-based approach is needed to promote good living and social participation in people with dementia.

Keywords Dementia · Stigma · Social inclusion · Ageism · Well-being

7.1 HEALTH AND AGE-RELATED DISCRIMINATION

Chronic diseases impose a burden at a global level. The increase in life expectancy led to a growing number of older people with chronic health conditions such as cardiovascular disease, cancer, and neurodegenerative disease. Huber and colleagues (2011) highlighted the need to reconsider the definition of health as “the ability to adapt and to self-manage, in the face of social, physical and emotional challenges”, rather than merely the presence or absence of a disease. The authors propose three domains of health: physical, psychological, and social health. Within this conceptualization, social health includes, from an individual perspective, three dimensions: (1) the capacity to fulfil potential and obligation; (2) the ability to manage life with some independence despite medical conditions; and (3) the ability to participate in social activities including work.

Beyond the individual level, a social-environmental level has been proposed (Vernooij-Dassen et al., 2022) which includes three different domains related to the structure (in terms of the type of social interaction such as social network size and composition, marital status, and frequency of contact), the function (such as emotional support and instrumental aids), and appraisal of the quality of relationships and interactions (related to the perception and interpretation of social contacts and consequent loneliness). Using the individual and social perspective, the authors argued that the individuals’ functioning does not depend on their capacities only. The behaviour of their social environment which may support but also hinder them from using their capacities may be equally important. Social factors can influence older adults’ psychological well-being and cognitive functioning, and they can enhance their cognitive reserve as well as they can moderate the progression of their cognitive decline (Samtani et al., 2022; Seifert et al., 2022). From this perspective, promoting social health and reducing isolation and discrimination can be considered as a treatment opportunity.

The role and importance of social aspects in promoting older adults' well-being and adaptation have been also discussed within the framework of age-related stigma and discrimination. A large body of literature outlined the role of stigma and discrimination toward ageing, frailty, and mental disease. Terms such as “ageism” (i.e., discrimination toward older adults), which was first proposed by Butler (1969), are used today to describe any kind of stereotype, prejudice, and discrimination toward a social group based on chronological age. It can be directed toward adolescents and older adults mainly by adults. Ageism toward older adults is now recognised as an important issue to be addressed to promote healthy Ageing. The United Nations General Assembly in their plan for the decade (2021–2030) of Healthy aging suggested, as a first action, to combat ageism. Stigma toward ageing is related to “how we think, feel and act towards age and ageing” focusing the attention on the role of the social context and the role of others and on how norms, policies, attitudes, and approaches can exclude people from access to facilities, services, and resources.

The stigmatisation of older adults in general, and of those with chronic illness specifically, can have a significant impact on health and well-being (Kang & Kim, 2022), thus implying stereotype internalisation by older adults through self-stigmatisation, isolation, and loneliness. The consequences of ageism and “self-ageism” also impact the access to care, and the quality of care for older people in different settings.

As mentioned before, stigmatisation of older people is even more important in the case of a chronic illness and, specifically, in the domain of mental health. The attitudes of mental health professionals toward psychological interventions with older people are influenced by negative ideas regarding the ability of older people to benefit from such treatments (Bodner, 2009). For example, in many countries, specific training for mental health professionals on the approach to mental disorders in older people is not available. Assessment criteria, pharmacological treatment, and psychotherapies are based on the work with adults and transferred to the work in geriatrics. Similarly, the research in these domains is lacking in addressing the specific conditions of older people.

Within mental health domains, neurodegenerative diseases, and mainly dementia, are considered a public health priority, looking at prevalence and incidence rates and the lack of a cure until now. The link between dementia and age is widely recognised and the prevalence of the disease increases with age, which is considered one of the most important risk

factors for dementia. However, adults can also be affected by dementia, and this condition is called “young onset dementia”. Since the prevalence of dementia is growing with age, people living with this condition can be exposed to a double type of stigma, one related to age (Ageism) and one related to dementia (demente-ism) (Brooker, 2007; Evans, 2018).

Dementia, a neurodegenerative disorder, is an umbrella term used to indicate a variety of conditions characterised by neuronal damage. The most prevalent type of dementia is Alzheimer’s disease which accounts for around 62% of all types of dementia followed by vascular dementia, frontotemporal dementia, and Lewy body dementia as the most frequent. Dementia, a brain disease, is characterised by a progressive decline in several domains of cognitive abilities such as executive functions, learning and memory, language, perceptual and motor functions, complex attention, and social cognition (DSM-5). The duration is up to 12–15 years. Cognitive decline has an impact on the person’s capacity to retain information and also to recall memories, communicate and understand others and the world around them, and to perform daily activities. The person becomes more and more dependent in managing daily life, thus relying on others to perform simple activities in the advanced stages of dementia. Another disease aspect, beyond cognitive and functional decline, is the presence of the so-called “behavioural and psychological symptoms” such as delusions, hallucinations, anxiety, depression, and agitation. These noncognitive symptoms represent a challenge for carers, impacting on the quality of life of people with dementia and their family caregivers as well representing the major cause of institutionalisation.

Dementia has long been considered as a biological disorder (Vernooij-Dassen et al., 2021) caused mainly by brain damage. The consequences of brain damage on cognitive abilities lead, as mentioned above, to people’s difficulties in verbal communication (understanding and expression), in their capacity to cope with everyday challenges such as managing finances, preparing meals, dressing, or moving around. Several needs of people with dementia are unmet. Not only practical needs but also emotional and relational needs. Kitwood (1997) along with other authors (Sabat & Lee, 2012) are among the first researchers who propose the necessity to consider the person with dementia instead of dementia, thus highlighting the concepts of Personhood, and Selfhood.

Kitwood addressed the issue of malignant social psychology to describe how people with dementia are approached and treated by others. In his book, he used several terms to describe the approach of carers such

as infantilization, intimidation, labelling by the name of the disease, invalidation, banishment, ignoring, mockery, and withholding.

All these terms outline the difficulty of professional carers to recognise and treat the person with dementia as a person, acting like it is not present in the interaction and the relationship. This way of approaching people with dementia has an impact on their experience of their condition. Many of the so-called “behavioural and psychological symptoms” of dementia can be considered as a reaction, a way to communicate, react or express unmet needs, or negative emotions related to the experience of the disease (Burley et al., 2021).

The work of Kitwood has been remarkable in the field of dementia care promoting a change in the understanding of the experience of people with dementia, and several actions have been undertaken to reduce stigma and social isolation. Nevertheless, the stigma toward people with dementia still needs to be addressed, since it has an impact on several aspects of the dementia journey from research to care and to social engagement.

7.2 STIGMA AND DEMENTIA: THE IMPACT

The impact of stigma toward dementia can be considered at different levels: the individual, the family, society, healthcare and welfare, research, and policies.

At an individual level, stigma can lead to feelings of shame, low self-esteem, a sense of uselessness, withdrawal from social interaction, social isolation, depression, and anxiety. People with dementia, challenged by the consequences of cognitive decline, experience several limitations which impact on their emotional balance.

Families are involved as well by experiencing feelings of shame, isolation, depression, and burden. Some authors suggest the term “courtesy stigma” or “associative stigma” to refer to the discrimination and prejudice experienced by people, because they are parents or relatives of a person with dementia (Van den Bossche & Scoenmakers, 2022). Another term proposed is the “affiliate stigma” to refer to the internalisation of the stigma by family caregivers with negative feelings toward themselves.

At the healthcare and welfare level, the stigmatisation of people with dementia can be observed at different stages across the care pathway. Since these aspects are related to the context, The multifaceted impact of stigmatisation in dementia will be discussed in detail.

At the societal level, the stigma of people with dementia can lead to the avoidance of contact and engagement, exclusion from social participation and involvement in social life, and the loss of friendships which in turn leads to social isolation and loneliness.

7.2.1 *The Diagnosis Disclosure*

Even if a lot of advances have been made for a timely diagnosis of dementia, a delay in diagnosis, which differs between countries across Europe and globally, is still observed, and it can last to 3–4 years from the onset of cognitive decline. Even after several public campaigns, the delay is still present and is related mainly to the reluctance of the person with dementia to seek help (37%), the lack of recognition by professionals of the signs of cognitive decline (33%), the attribution of cognitive changes to age (26%), and to the length of the diagnostic process (12%) (Woods et al., 2019). These results outline a combination of a lack of awareness by both professionals and people with cognitive problems and their reluctance to seek help, which is frequently associated with the fear of stigma.

The diagnosis disclosure is also another challenge in dementia care. Even if in most countries it is a right for people to receive information about their health condition and it is their own decision to share health information with others, in the case of dementia this right is not fully respected. In a survey collected in 5 European countries, several differences emerge. The direct communication of the diagnosis to the person with dementia ranges from 40% to 99%, and the lack of direct communication is partly related to the expressed wishes of the person itself while, in large part, it is related to the decision of the healthcare professional or an explicit request of the family caregiver (Woods et al., 2019). In other studies, only 34% of primary care physicians communicate the diagnosis to the person with dementia (Low et al., 2019). Barriers to disclosing the diagnosis of dementia are at different levels (Wollney et al., 2022). At the clinician level, some reported barriers are related to the lack of training, the perceived lack of benefit in diagnosing dementia, the concern for the patient or the caregiver's response, and the capacity of the person with dementia to understand and retain information. At the patient/family level, the barriers are related to the lack of the ability to understand the diagnosis, and to the fears related to the disease. A systematic review (Yates et al., 2021) focused on the issue

of diagnosis disclosure from the perspectives of healthcare professionals, carers, and people with dementia. The authors outline that research is needed to understand the perspectives of people with dementia regarding the process of diagnosis disclosure which can help the development of an approach which is reasonable for all actors involved in the process. In other words, there is a lack of research regarding how people with dementia experience the disclosure. It is difficult to disclose the diagnosis to a person with dementia and there is limited research on their experience within this process. Considering dementia as a process of decline, characterised by a loss of capacity, may lead to the person being excluded and losing their agency. Kate Swaffer (2015), a person with dementia, described “prescribed disengagement” (the post-diagnostic prescription to give up some of their usual activities) as increasing stigma and discrimination, reducing self-esteem, and devaluing and demeaning the person affected by this condition. This process of de-personalization leads to the exclusion of the person with dementia from being an agent, a person with rights in need to be heard by others. The consequences can have a significant impact on the person’s good living and social health.

7.2.2 *Advance Care Planning*

In several dementia care pathways, the diagnosis disclosure should prepare for care planning or advanced care planning looking to the future of the person with dementia, where the loss of capacities may limit their chance to take part in some decisions about care.

In this domain, diagnostic disclosure plays an important role and only if people with dementia are aware of their conditions, a discussion about the future is feasible. We can mention two main barriers at this level. The first one is related to the attitude of professional carers who avoid talking about the prognosis of the disease. As for the diagnostic disclosure, prejudice about the capacity to understand and discuss care options is a limitation. Furthermore, the absence of a planned process for supporting people with dementia to accept and adapt to the new situation makes planning difficult. There are few structured approaches to follow-up the patient elaboration of the new information, which can support carers and people with dementia, and facilitate further discussion and a better way to deal with trauma-related to the loss of capacities and the planned future (Yates et al., 2021).

7.2.3 *Shared Decision-Making*

The post-diagnostic phase of dementia, which can last for several years, is usually divided into three stages that are mild, moderate, and severe (or advanced) dementia. The brain damage is more extended, and the loss of cognitive abilities is significant with consequences on the loss of autonomy and a greater dependency. Along the trajectory it is a great challenge to decide when the person with dementia loses their capacity to make decisions and also to establish what the content of the decision is. For example, at the mild-moderate stage, the person may be unable to understand a complex situation, but they are still capable of agreeing/disagreeing with aspects related to daily life, such as participation in activities or comfortable/uncomfortable situations.

The most important barriers in long-term care toward shared decision-making and care planning for people with dementia are the attitudes of care professionals and family caregivers, the lack of professional training in communication skills as well as norms and job overload (Mariani et al., 2017). As in the diagnosis disclosure and advance care planning, the lack of involvement of people with dementia in decisions is related to the attitude of others toward the person with dementia and the non-recognition of their ability to communicate or express preferences and wishes. Even in the severe phase of dementia, the person is still able to react to external stimuli and express at least states of pleasure or pain, comfort, or discomfort. What is needed is a change in the way carers look at the person with dementia, recognising strengths along with limitations.

7.2.4 *The So-Called Behavioral and Psychological Symptoms of Dementia (BPSD)*

Kitwood (1997), writing about malignant social psychology, uses the term “labelling”, which can be understood as naming a person by their disease or symptoms. In the domain of dementia, there is a group of symptoms labelled as behavioural and psychological symptoms of dementia (1996). This category includes aspects related to perceptions and thoughts (delusions, hallucinations and misperception), mood (anxiety, depression, apathy and emotional lability), behaviour (agitation, wandering, verbal and non-verbal behaviour which can be aggressive or not), sleep and eating changes. These features are considered as symptoms

of dementia related to brain damage, which means that they are meaningless and the main approach should consist of controlling and restraining the person living with dementia. From the perspective of Person-centred care (Kitwood, 1997) the behaviour can be considered as an expression of unmet needs or as an expression of challenges or difficulties in coping with changes related to cognitive limitations. Subsequently, Stokes (2000) suggested the use of the term “challenging behaviour” to describe these symptoms in order to understand the determinants of the behaviour, thus underlining the need to find the meaning of certain behaviour in terms of the needs, desires, and preferences of the person living with dementia.

In the NICE guidelines (2006), the term “behaviour that challenges” has been used to outline that a certain behaviour can be seen as a reaction or a communication of the person regarding the experience of unmet needs or distress or the absence of engagement. The main aim is to cope with the changing situation and to maintain balance and well-being. Recently, the NICE guidelines (2018) and the Italian guidelines for diagnosis and treatment of MCI and dementia use the term “non-cognitive symptoms” of dementia, while other countries such as Canada or Australia suggest others as well. What is important to consider is the effort needed to reframe the concept and to shift from a “pathologizing” approach to behaviour (Dupuis et al., 2012) toward an approach where the behaviour is seen as a meaningful communication, and the challenge is related to the capacity of carers to understand, underlying the determinants of the behaviour and respond appropriately.

Burley et al. (2021) reported the perspectives of people with dementia and their carers about BPSD. The results outlined the need for a reframing of the concept for a better understanding of the experience of the person with dementia. For example, the authors discussed that the use of the term agitation can be misleading, while a better description such as being frustrated or receiving discriminatory behaviour or inadequate support can better represent the real experience faced by the person themselves. The debate around the issue of behaviour in dementia highlighted the difficulty of carers in particular, but also of the public in general, to recognise an active role of the person with dementia in the interaction with the environment and others (carers, friends, and neighbours).

7.2.5 *Behaviour Across the Trajectory of Dementia*

As mentioned before, the progressive loss of cognitive abilities, specifically the capacity to use verbal communication, implies the use of non-verbal communication as a main skill to interact and exchange with others and the world. Motor activities (body language) as well as facial and vocal expressions become the most used tools to express and react to challenges faced by the person with dementia. Labelling these modalities as “symptoms of disease” implies denying the presence of the person, their history, their preferences and wishes, and their difficulties.

In this way, the process of objectivation (Kitwood, 1997) can lead to a complete absence of the other. The lack of awareness about the capacities and abilities of the person with dementia, even in the severe disease stage, undermines the inalienable human rights of the person.

7.3 GOOD LIVING WITH DEMENTIA

The lack of a cure for dementia stimulates a large body of research aimed at promoting the well-being of people with dementia and their family caregivers. In recent years, there has been a global effort to refrain the vision of care for dementia from a “giving up” approach where, in the absence of treatment people are invited to “give up work, study, and to go home and live the time left” (Swaffer, 2015), to a more balanced approach where the focus is on good care and on promoting the quality of life and adaptation to the consequences of the disease. To achieve this objective, many researchers focus on interventions aimed at promoting psychological and social well-being. A large field has been developed regarding non-pharmacologic interventions or more specifically psychosocial interventions aimed to support people with dementia to adapt and manage their conditions while preserving a sense of self, identity, and social participation. Quinn et al. (2022) report the key areas identified by people with dementia regarding the concept of living well. The key concepts reported are mostly related to psychosocial aspects such as being engaged, having an active lifestyle, preserving positive relationships with others, having a good living situation and environment, having security, getting on with life, being able to get out and about, a positive outlook on life, being able to cope, having independence, and having a purpose in life. As discussed by the authors, all these domains are related to both psychological and social aspects. In the work of Kim and Shin (2023),

similar results are reported and four domains of the concept of living well have been identified: physical (maintaining independence and symptoms management); psychological (psychological health, emotional balance, and preservation of a sense of self and identity); social relationships (social relation, community connectivity, support policies).

What emerges from all these conceptualizations is the important role of carers, environment, and context in supporting and promoting the chance of living well with dementia. Despite the consequences of the disease that can undermine the person's abilities, the social environment can play an important role in recognising the strengths and resources of people with dementia, in facilitating their need for independence, and in using the appropriate approach and services to manage symptoms. Similarly, at a psychological level, the empowerment of people with dementia is needed. Being recognised by others, receiving support to cope with challenges, and having trained professionals and available interventions to develop a positive approach are necessary to allow people living with dementia to maintain their quality of life.

Furthermore, the social environment can have an important role in ensuring engagement and participation in community life, preserving social relationships, and supporting inclusion in the social environment. Finally, the health care and welfare systems need to build skills and approaches which are not focused on meeting basic needs exclusively, but also on promoting a more person-centred approach to meet other individual needs such as inclusion, utility, belonging, participation as well as on preserving dignity.

7.4 SOCIAL HEALTH AND DEMENTIA

In the recent two decades, a significant change occurred in the global approach to dementia. The World Health Organization stated that dementia is a public health priority and a global plan was proposed to tackle the burden of the disease. In many countries, a national plan for dementia has been developed where psychosocial interventions are highly recommended (Chirico et al., 2021). The interventions are not only addressed to manage symptoms but also to promote living well with dementia. Beyond specific interventions directed to people with dementia and their caregivers, a large body of initiatives addressed the issue of stigma and social inclusion. Recently, the promotion of dementia-friendly communities in different countries has aimed to reduce stigma

while promoting the social health of people with dementia. The main pillars of the concept of dementia-friendly communities are raising public awareness about dementia, training the public to deal with people with dementia and to facilitate their participation and inclusion, and adapting the social context and environment to the needs and challenges posed by the disease. The dementia-friendly approach aims to involve people with dementia in decisions regarding themselves. This perspective involves not only people with dementia, family caregivers and health care professionals but also public and private sectors such as banks, public services, groceries, and many other sectors.

Social inclusion and participation can be also promoted using specific interventions such as social activities, adapted work opportunities, visiting museums, and so on.

Promoting social health and social inclusion can have different impacts on the journey of people with dementia. It can play a role in the prevention of cognitive decline and in enhancing cognitive reserve (Vernooij-Dassen et al., 2022), but it can also impact the quality of life, well-being, and the excess of dementia-related disability.

7.5 CHANGING NARRATIVES

Good living with dementia is a complex issue and encompasses different domains of life. The shift in the approach to chronic disease in general, and to dementia in particular, enhances the capability to focus on the experience of the person and of their carers rather than looking only at the disease. To achieve the objective a broad approach is required and different domains need to be addressed.

Certainly, research for a cure is needed, but while waiting for a cure, it is still crucial to support people with dementia and their caregivers. This support can be provided through different actions at individual, family, societal, and governmental levels. To support people with dementia, the recognition of their being a person with values, capacities, and strengths is needed. To achieve this objective, a different narrative of the dementia experience is necessary. Changing narratives, from a negative and helpless one to a more positive and empowering one, can be achieved if the dynamic between individual and society is addressed.

The example of stigma is very meaningful. Public stigma and self-stigma can be seen as an interactive process. What others think, feel, and act toward a specific group is internalised by at least part of the

target group. In the case of dementia, negative views have an impact on the experience of the person affected, influencing their quality of life, and their ability to participate in social life, preserve independence, and manage their life. From this perspective, the social health framework including both individual and social-environmental domains can be used as an umbrella concept to advance both research and practice in dementia care.

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