

Cahill, S. (2018). *Dementia and human rights*. Bristol: Policy Press, 252pp. ISBN: 978-1447331407

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There are few diseases that can make people who are diagnosed with them and their relatives particularly hopeless and often also helpless. One of such diseases is dementia. The threats and challenges of dementia are felt globally. According to the World Health Organization (WHO), nearly 9.9 million people around the world develop dementia each year; in 2015, there were 47 million people in the world living with dementia, and this number is predicted to almost triple and reach 132 million by 2050 (WHO, 2017). These figures must be multiplied by a factor of at least two if we broaden the notion of the term “people living with dementia” by adding the immediate family members, usually spouses. Dementia typically occurs in people aged over 65 years; about 5% of the world’s population of older persons has dementia. With ongoing and accelerating population ageing the incidence and prevalence of dementia are expected to grow. However, dementia is getting ‘rejuvenated’: young onset dementia (defined as the onset of symptoms before the age of 65 years) is accounting for up to 9% of cases (Alzheimer’s Disease International & WHO, 2012).

The progress in exploring the etiology and pathogenesis of dementia has been impressive. The involvement of cellular and molecular mechanisms can be better understood and that there are several forms of dementia. In addition to Alzheimer’s, there is also vascular dementia, dementia accompanying other brain diseases – symptomatic dementia, and the recently discovered LATE (National Institute on Aging [NIA], 2019). Despite the evident progress, the cure is not available, this means that people diagnosed with dementia must live with dementia and adjust to the challenges associated with this disease. The same applies for their relatives, care givers, and friends. However, the good news is that many manifestations of dementia are manageable, and while the underlying illness is not curable, its course might be modifiable by a good dementia care plan. Moreover, an important fraction of dementia is considered preventable (Livingston et al., 2017). The important conclusion is that in anticipation of future radical remedies significant efforts in dealing with dementia should focus on its management and assistance to people living the rest of their lives with this disease. Adjusting to dementia must be recognized and promoted along with continuous efforts of understanding and controlling the underlying causes of the illness.

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Most of the above introductory contemplation reiterate the reasoning of the book, *Dementia and Human Rights* by Suzanne Cahill. According to Cahill, adjusting to dementia means, in the first instance, discovering, revealing and utilizing the remaining abilities and strengths of people living with the disease in order to “overcome social and structural barriers which can create additional disabilities and which can threaten human rights of people with dementia”. To achieve this, argues the author, we need to deconstruct dementia and transport it from an “isolated island of cure and care” to a “broader world of rights”. In more practical terms, this would imply better understanding of dementia, and translating this new understanding into policy options. Such policy options should be based on a “rights based approach, (which) demands accountability, dignity, fairness and social action”. In other words of the author, the task is “to elevate needs to rights” so that the lives of people with dementia and their relationships with a broader society be framed within “a system of rights and obligations”.

As follows from the title and content of the book, its central premise is that dementia must be brought into the realm of human rights. Such a transfer would open an opportunity to reconsider the situation of people living with dementia against the well-established framework of international legally binding instruments on human rights. The first essential step for bringing dementia into the realm of rights, suggests the author, is to conceptualize dementia as disability.

Conceptualizing dementia as disability, the author elaborates, can bring various benefits. Most importantly, such an approach would place people living with dementia under the political and legal umbrella of the legally binding international instrument – the United Nations Convention on the Rights of People with Disabilities (CRPD) and, consequently, give them a full entitlement to all the human rights embedded into the CRPD (United Nations, 2006). The author rightly notices that although the CRPD, unlike the national human rights acts, is not legally enforceable in court, “it offers people living with dementia the potential for legal protection and entitlement to services”. At the same time, regarding dementia as disability does not exclude it from the consideration and exploration by biomedical research and health and social care practice. In this connection, the author advocates for the advantages of considering dementia simultaneously as “a health condition, a social construction and a neurological impairment influenced by a broad range of factors including biological, psychological, economic and cultural factors”.

The author defines a central and unifying theme of her book as “recognition of the civil, political, social, economic and cultural rights the individual living with dementia possesses”. The applicability of the CRPD to reframing the dementia as a human rights issue and promoting the rights of persons living with dementia is substantiated throughout the book. Based on the CRPD, the author identifies several individual’s rights most pertinent to persons with dementia:

- (1) Equal recognition a person with dementia before the law as a holder of rights and obligations. This right refers to the legal capacity of persons with disability outlined in

the Article 12 of the CRPD. For persons with dementia, it envisages the provision of assistance in cases when persons cannot exercise their legal capacity.

- (2) The right to an early diagnosis and its appropriate disclosure or non-disclosure.
- (3) The right to treatment and rehabilitation based on multidisciplinary assessment and focusing on enablement as an approach aimed at supporting people “to be and to do what they have reason to value” and to enable them “to function at their optimal capability”.
- (4) The right to live independently and be included in the community. Implementation of this right requires availability and accessibility of home care services for persons with dementia, and a range of options of long term care for people with severe dementia, which are considered attractive by both the people with dementia and their family members.

The articles of the CRPD are addressing four broad themes: equality, autonomy, participation and solidarity. At the same time, the author rightly argues that some articles of the CRPD should “be re-worked to make them more inclusive of the individual living with dementia”. For example, elaborates the author, the CRPD focuses on promoting the rights of people with disabilities living in the community; it omits the issues related to the rights and needs of people living in institutions - most people with dementia belong to the latter category. The selection of human rights that are relevant to individuals diagnosed with dementia who live in care homes or in nursing homes include the right of freedom from torture or cruel, inhuman or degrading treatment or punishment; the right to privacy; the right to access the physical environment; and the right to participate in meaningful activities. All the above rights refer to a good quality of life at any stage of the dementia illness.

CRPD provides the legal norms and standards for protecting the rights of persons with disability. It also offers a framework for designing and implementing national policy in disability. Moreover, as the international legally binding document, CRPD sets the well-established international *procedure* for regular reporting and the *structure* for monitoring the implementation process (United Nations Department of Economic and Social Affairs, n.d.). Thus, linking international and national policies on dementia to CRPD would help to enforce the implementation by and compliance of national governments.

Another international policy framework, to which the author makes numerous references, is the *WHO Global Action Plan on the Public Health Response to Dementia. 2017 – 2025* (WHO, 2017), which was developed ten years after the approval of the CRPD. Among the seven cross-cutting principles of the Global Action Plan, there is the principle of “Human rights of people with dementia”, as well as the principle of “Empowerment and engagement of people with dementia and their carers” and the principle of “Equity”. The Global Action Plan makes references to the CRPD in its Action area 1 “Dementia as a public health priority” and Action area 2 “Dementia awareness and friendliness”.

One more policy framework might be on the horizon of international debates: The Convention on the rights of older persons. Such a prospective legally binding document might fill the above-mentioned gaps of CRPD with regards to dementia. The nucleus for developing a draft Convention – the United Nations *Open-Ended Working Group on Ageing* - has been in place for nine years (United Nations, 2011), and the *Independent Expert on the enjoyment of all human rights by older persons* was designated in 2014 (United Nations, Human Rights Office of the High Commissioner, 2019). Meanwhile, the political decision of the UN legislative bodies (i.e., General Assembly) has not been taken yet owing to the lack of consensus among the UN Member States.

The book includes useful references to selected models of national policy on dementia, which contain “moderately strong” commitment to human rights principles. The author’s own choice of good models is based on the assumptions that such model policies must address discrimination, marginalization, and exclusionary practices and should be inclusive of human needs, personhood and human rights of people with dementia. Among the countries with exemplary policy models the author mentions Australia, Norway, Scotland and the US; Scotland being also the first country that elaborated in 2009 the national *Charter of Rights for people with dementia and their carers*.

The author is quite persuasive in her central arguments for addressing the challenges faced by persons with dementia and their families from a human rights perspective. Equally important, she presents her arguments in a crisp clear language, which does not hide her dedication and passion for the subject. Among other benefits of reading the book is that it contains an excellent overview of key concepts and terms related to the areas of both dementia and human rights.

A concluding chapter of the book gives an opportunity to summarize the entire content and outline the perspectives. The subtitle of the concluding chapter, “grounds for hope”, attests to a positive view of the author. The reader is eager to pick up the concrete recommendations how to advance the positive future for people with dementia. The author formulates two key recommendations; the first is addressed to policy-makers and, the second, to practitioners working with people with dementia:

- (1) “Policy-makers need to be more cognizant of human rights – social, economic and cultural along with civil and political rights”.
- (2) “Practitioners need to undergo training in dementia and human rights and use a human rights framework in their everyday practice”.

In the two recommendations, the policy-makers and practitioners are addressed as major “doers”; one would hardly object such designation, but what about family members and other informal caregivers who are referred to throughout the book?

The two recommendations placed by the author are of a very general nature and sound more like goals or slogans, while concrete measures for reaching these goals are missing. Meanwhile, various specific areas of concern and measures to address those concerns are mentioned throughout the book: adaptation of physical and living environment, including establishment of small scale residential (housing) units; development of appropriate gadgets and services, which, I would add, in turn entails concerns of their safety and compliance with human rights of users; poorly designed care environment and inappropriate working conditions of care givers; inadequate funding of care systems; et al. The challenging task of securing legal capacity of people with dementia is thoroughly discussed in the book, but, again, concrete approaches and methods of addressing this task are not distilled and concentrated in a set of recommended policy measures. It would have made sense to consolidate these and other concrete recommendations into some sort of an outline for policy framework.

Another obvious question: what is the cost of measures needed for transporting dementia from an “isolated island of cure and care” to “a broader world of rights”? The various measures, including those listed in the previous paragraph, might be pricy. Dementia is a costly problem. Below is a quote from the Global Action Plan on the Public Health Response to Dementia:

In 2015, dementia costs were estimated at US\$ 818 billion, equivalent to 1.1% of global gross domestic product, ranging from 0.2% for low- and middle-income countries to 1.4% for high income countries. By 2030, it is estimated that the cost of caring for people with dementia worldwide will have risen to US\$ 2 trillion, a total that could undermine social and economic development globally and overwhelm health and social services, including long term care systems specifically (WHO, 2017).

Nearly 85% of costs are related to family and social costs, rather than medical care (Livingston et al., 2017).

The cost of adjustment to dementia might be more affordable for economically advanced countries which can mobilize sufficient financial resources and which also have well established public systems of care and support. No wonder, all exemplary policy models quoted by the author are coming from the economically advanced countries. However, in author’s own words, even in those countries “there is a massive underfunding of all services for people living with dementia”(Cahill, 2018). Moreover, there are also “diagnostic gap” and corresponding “treatment gap” in high-, middle- and low-income countries. Filling these gaps and introducing new diagnostic and treatment techniques would require significant investments. Meanwhile, nearly 60% of people with dementia currently live in low- and middle-income countries and most new cases (71%) are expected to occur in those countries (WHO, 2017).

The burden of dementia, including its financial burden, is shared by families, and, again, this burden is particularly big in less economically and socially advanced countries. While in high-income countries the share cost of informal care related to dementia amounts to 45%, in

low- and middle-income countries it reaches 85% (ibid.). Another major parameter of financial impact for people with dementia and their families in various countries is reduction or loss of income (ibid.).

“Transporting dementia into the realm of human rights” implies policy measures aimed at implementing the social and economic rights. The author acknowledges that implementation of these “positive rights” is resource-intensive. Thus, the selection of policy measures and introduction of new approaches and techniques for adjusting to dementia should be thoughtful and concrete to make the response to dementia appropriate, affordable and sustainable. Such measures are indispensable while we are waiting for the future medical cure and care to “replace and reduce some of the cost” (Livingston et al., 2017) and relieve the humanity from one of its big challenges and threats.

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