

## ESSAY REVIEW

Positive Psychology Approaches to Dementia (2016). Chris Clarke and Emma Wolverson, (eds.). London: Jessica Kingsley Publishers. ISBN 978-1-84905-610-6

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### Aims of the book

To begin this book with a negative and *problematizing* narrative about dementia would be at odds with its central aim, which is to explore the psychological states and experiences that might make it possible not merely to live with the condition but to live positively. Although dementia remains a stigmatised and feared condition that is easily described in terms of loss, decline and pathology, this book instead seeks to explore an alternative, positive narrative that reflects people's actual experiences of living with dementia.

It is easy to be sceptical of the notion of maintaining wellbeing and having positive personal and social experiences while living with dementia. It may be easy to assume, as many previously have done, that the changes in cognitive, social and functional abilities that occur in dementia severely limit if not preclude genuine experiences of wellbeing. A natural concern might also be that in directing attention towards the possibility of such experiences we risk invalidating people's negative experiences and struggles. Whether living with dementia, at a subjective level, involves a degree of suffering is a factor that continues to be investigated, in recent years accounts of positive experiences in living with dementia have emerged. This has coincided new insights into the value of open inquiry into people's lived experience employing phenomenological and constructionist perspectives research methods.

At the same time, principles and constructs from the field of positive psychology are increasingly being applied to understanding how people age successfully and can respond positively to adversity related to living with long-term health conditions. So-called second wave positive psychology approaches are very relevant here as they are concerned with how positive and negative states interact and are contextually defined. Documenting and understanding such processes and experiences in dementia have important implications in terms of enhancing

conceptual accounts of wellbeing and quality of life, as well as re-contextualising and de-stigmatising the condition.

### The intended audience and style of writing

This excellent volume provides a compassionate and challenging approach to dementia. It is an invaluable resource for people living with dementia, their carers and researchers. Christine Bryden says in the foreword that: "If only this work, this type of thinking, had been available when I was first diagnosed, how different my experience would have been." The strength of the text is in the thorough analysis and explanation of current research findings, carefully documented.

### How the book is organised

To consider the possibility of living positively with dementia, Chapter 1 explains the need to recognise the influence of biomedical discourses of loss and pathology that usually surround the condition. Such discourses imply that dementia automatically dominates and devastates a person's life. As such, people living with dementia are seldom asked if (and how) they still experience achievement, enjoyment, love, hope, humour, growth and spirituality. The assumption that people with dementia do not and cannot have these kinds of experiences is therefore maintained. Positive Psychology has much to offer in terms of understanding how human flourishing develops in conditions of environmental adversity. We now have statistical data spanning 50 years that shows that populations increasingly value aspirational goals related to social wellbeing and happiness. Specifically, healthy life expectancy, perceived social support, trust, generosity,

freedom to make life decisions, fairness and the environment, are identified as crucial to personal wellbeing. Income is relevant, but not of the highest importance. Humans experience increased wellbeing it seems, when they feel part of a meaningful whole for which they share responsibility. These are the important underpinnings for happiness and coping well when adverse circumstances are experienced.

Chapter 2 shows how a narrow, illness-focused construction of dementia has inadvertently fostered negative stereotypes and stigmatising social processes that have obscured our understanding of positive experiences and outcomes. However, social discourses surrounding dementia are now undergoing seismic changes, led by people living with the condition and sustained by concerted and international moves toward empowerment, inclusion and self-advocacy. In this new and evolving narrative, people living with dementia can be seen as active agents in their unfolding experience of the condition who, despite the formidable challenges they face, retain the capacity and motivation to increase their wellbeing and find ways to flourish. Chapter 3 discusses the important concepts of wellbeing and quality of life in relation to dementia, highlighting, in particular, how aspects of the former may not always be fully captured when we attempt to assess the latter.

Chapters 4 and 5, describe the ways in which hope and humour, respectively, might contribute to wellbeing in dementia and illustrate how personal experiences of these constructs in dementia can have varying meanings and significance. Chapter 4, for example, addresses the question: "How can people with dementia build hope?" People with dementia and their caregivers have described a range of ways they cope in their everyday lives and re-assign meaning to their experiences. Throughout this literature there exist accounts of people expecting the best and maintaining a positive outlook on life and the future consistent with the future orientation aspect of hope that is central to most theories (see earlier in the chapter). A sense of determination and agency to live life to the full in spite of a diagnosis of dementia is also echoed within this literature. Framing people with dementia as active in facing and fighting their illness suggests that they may also be active in the process of hoping rather than passively waiting for a cure, or succumbing to despair. Accepting dementia as a part of one's life appears to be key in learning to live with this condition and, in turn, maintaining hope has been described as key to acceptance as it can allow people to focus on upholding meaning and purpose in their lives rather than dwelling exclusively on their illness.

Chapter 6, explores resilience and how this overarching concept offers an alternative to narrow models of successful ageing, therefore promoting a more inclusive approach to understanding how people with dementia can continue to use personal and social assets to maintain wellbeing in the face of the varied challenges the condition brings. Chapter 7 centres on a challenging question: whether the personal growth known to be possible in ageing and in relation to adversity due to ill health or trauma might also be possible for people living with

dementia. In doing so, this chapter examines the potentially controversial possibility that some people may experience personally transformative experiences because of dementia, which, in turn, lead to the experience of new and different forms of wellbeing. Chapters 8 and 9 cover the important constructs of creativity and spirituality and wisdom. In doing so, these contributors explore how experiences in each of these domains are not only possible in dementia, but are potentially pivotal in preserving identity, personhood and wellbeing.

Chapter 10 begins with a brief overview of debates relating to a positive psychology of ageing in general, particularly for people with what are now termed 'high support needs'. It then moves on to consider what might loosely be termed 'a positive psychology of dementia', with a focus on the notion of personhood, before summarising current thinking on positive relationships for people with dementia. However, the book moves well beyond this and argues that a relational view of dementia cannot focus on the needs of any one individual or group of individuals, but rather must address the needs of all those involved in supporting people with dementia. The 'Senses Framework' considers how it might be used to create an 'enriched environment' that facilitates positive relationships in dementia care in a diversity of settings.

Chapter 11 explores the positive aspects of providing care to a person living with dementia by first examining the role of positive emotions in challenging circumstances. It provides examples of positive aspects of care identified in research with caregivers of older adults and people with other chronic health conditions. It then proceeds to explore the potential for dementia caregivers to identify and experience positive aspects of caregiving, using examples from research with informal caregivers providing care to people living with dementia. This chapter focuses on informal dementia caregivers, who are usually family members or friends of the care recipient (i.e., the person living with dementia).

The final chapter, Chapter 12, provides an initial meta-level framework for conceptualising positive experiences and outcomes in dementia and some of the clinical and public policy implications of taking a contextualised, positive psychology approach to wellbeing in dementia are proposed.

## Thesis

To consider the possibility of living positively with dementia we must recognise the influence of biomedical discourses of loss and pathology that usually surround the condition. Such discourses imply that dementia automatically dominates and devastates a person's life. As such, people living with dementia are seldom asked if (and how) they still experience achievement, enjoyment, love, hope, humour, growth and spirituality. The assumption that people with dementia do not and cannot have these kinds of experiences is, therefore, erroneously maintained.

Positive Psychology has much to offer in terms of understanding how human flourishing develops in

environmental adversity. We now have statistical data spanning 50 years that show that populations increasingly value aspirational goals related to social wellbeing and happiness. Specifically, healthy life expectancy, perceived social support, trust, generosity, freedom to make life decisions, fairness and the environment are identified as crucial to personal wellbeing.

The person-centered perspective theory places the preservation of personhood, which does not and should not rest upon a person's cognitive status, as a central concern in maintaining positive wellbeing. Personhood therefore has dynamic qualities with the 'potential to evolve' insofar as social environments and, arguably, public discourses can facilitate this.

Wellbeing in dementia is underpinned by the achievement and preservation of four global, subjective, states that represent core psychological needs. These are described in terms of a sense of personal worth, a sense of personal agency, a feeling of being of use to and accepted by others and having hope that personal needs for psychological security will continue to be met. The social environment around the person with dementia should be attentive to and foster these global subjective psychological states and associated needs, in order to support and maintain the person's emotional wellbeing and quality of life.

The starting point in positive psychology is to enquire about what is working, what remains and what is right in our lives that allows us to experience positive wellbeing. Applied to dementia, this perspective underlines the importance of highlighting and preserving wellness, rather than treating illness. Positive psychology brings an additional layer of valuable concepts and perspectives on what wellbeing is and how it might be attained within the context of the challenges and constraints that arise from the condition. Thus, positive psychology models of wellbeing and flourishing have the potential to inform person-centred approaches to dementia and this can be conceptually illustrated in many ways.

Social roles relate to wellbeing. There is evidence within psychology to demonstrate that having valued social roles in later life protects and enhances self-esteem, self-identity and serves as a buffer against adverse events. Members of a community are able to draw strength and resilience from the presence of its members who are closer to death/living with limiting conditions. Opportunities to share life-defining experiences are likely to foster pro-social competencies and hope in community members of all ages. People in earlier life learn from seeing how their co-members of society in later life respond to adversities and cope naturally with significant life-defining difficulties. If people in later life are contained away from the mainstream of society and/or are mainly talked about in terms of negative attributes (e.g., pity), then it is likely that the response to them will be fear and denial, leading to lost opportunities for learning resilience.

## Definitions

The Values in Action (VIA) framework comprises 24 character strengths, or positive personal traits, that are categorised into six sets of virtues - morally valued dispositions that apply across cultures. Virtues span wisdom and knowledge (including creativity and curiosity), courage (which includes perseverance and zest), humanity (including love and kindness), justice (e.g., fairness and also teamwork), temperance (which includes forgiveness) and transcendence, which involves character strengths such as humour, hope and gratitude, held to 'forge connections to the larger universe and provide meaning'.

The (PERMA) framework identifies five measureable dimensions of wellbeing - positive emotion, engagement with activity, positive relationships, meaning (a sense of purpose and a connection with something greater than oneself) and accomplishment. These are primarily framed as positive outcomes, which in combination define a state of flourishing. Empirical work supports this multi-dimensional approach to defining wellbeing and indicates that these are separable dimensions. This approach has the advantage of combining social factors and relationships with individual internal resources in defining positive wellbeing and it provides an overarching framework for the measurement of wellbeing and flourishing.

Resilience might be defined as 'the capacity for successful adaptation, positive functioning, or competence despite high risk, chronic stress, or prolonged or severe trauma'. Resilience is seen as a naturally occurring phenomenon in the individual that will naturally prevail unless specific conditions occur. Every individual, irrespective of age, can protect their resilience through the life-span by resisting the internalisation of negative stereotypes and positively valuing the experience of later life. There are several conditions necessary for fostering resilience. These include a sense of a secure base, self-esteem and a sense of agency (having internal regulation over one's own life conditions and decisions). Optimism and positive expectancy also provides a counter to those negative societal expectancies about later life such as being 'past it' being a 'burden', having 'diminishing powers' and suchlike, which can result in individuals acting down to negative beliefs, weak social roles and demoralisation about later life.

## Conclusions

The authors' experiences of creating and editing this book and of conducting research into positive experiences in dementia reflect the dialectics of positive experiences and emotions. On the one hand, they were inspired by how re-defining challenges and losses involved in dementia which can be accompanied by, or even promote experiences of hope, humour, resilience, meaning and connectedness, as people strive to maintain their wellbeing. On the other hand, there is the continuous need to bear in mind that not everyone living with dementia has such positive

experiences. Expecting people with dementia to have these experiences would be invalidating and likely to promote further negative experiences.

This book is full of compassion and is delivered with high standards of bibliographical citations combined with respect for research participants so that it can confidently be recommended to everyone involved in living with dementia as well as to those in a caring role personally and professionally.

## Conflicts of Interest

The author declares no conflicts of interest.