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The Social Construction of Dementia: Implications for Healthcare Experiences of Caregivers and People Living with Dementia

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Abstract

Globally, systems have invested in a variety of dementia care programs in response to the aging population and those who have been diagnosed with dementia. This study is a qualitative secondary analysis of interview data from a larger study investigating stakeholder perceptions of programs that support caregivers and people living with an Alzheimer's Disease or Alzheimer's Disease-related dementia (AD/ADRD) in five North American jurisdictions. This study analyzed interviews with individuals living with an AD/ADRD and caregivers of individuals living with an AD/ADRD ($n = 11$). Thematic analysis was conducted to understand how the perception of dementia may have shaped their engagement and experience with healthcare systems. Our analysis resulted in three main themes of care users' experience: (i) undesirable experience owing to the overarching negative shared understanding and stereotyping of dementia; (ii) dismissal throughout disease progression when seeking health and social care support; and (iii) dehumanization during care interactions. The findings carry critical social and clinical implications, for example, in informing person-centered approaches to care, and communication tools clinicians can use to enhance provider, patient, and caregiver well-being.

Keywords

access to care, clinician-Patient relationship, healthcare planning or policy, qualitative methods, patient expectations, dementia

Introduction

A considerable body of literature seeks to understand how, where, and by whom the meaning of dementia is constructed.[1-5] Historically, dementia has been understood to mean imbecility associated with aging, divine punishment, evil possessions, and senility.[5] In fact, the term "dementia" originated from the Latin word "demens" or "madness" which speaks to its etymology and the misconceptions of dementia that persist today.[6] The construction of its meaning and how it is perceived by both persons living with dementia and society at large is mainly informed by misconceptions, negative stereotypes, and stigma.[1-5,7,8] Some misconceptions endured in society are also enacted in clinical practice. Clinicians can harbor stigma and often dismiss symptoms of dementia.[9] There are patterns of discrimination in acute care settings, with people who present with confusion receiving less contact time, infantilization by hospital staff, and inappropriate discharge.[10] Misconceptions about dementia also shaped healthcare training. With the exception of geriatricians, few healthcare workers are explicitly trained in dementia care.[10] This contributes to a cascade of negative events among people living with Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD), including emergency room visits, institutionalization, and premature death.[10]

The internalization of discriminatory practices in healthcare can impact the everyday experiences of people living

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Social Construction Of Dementia

Peter Burke,Jonathan Parker

Social Construction Of Dementia:

The Social Construction of Dementia Nancy Harding,Colin Palfrey,1997 This text outlines the limited knowledge base about dementia and covers the effects which that has on the design of services for people with dementia The authors have researched designs and methods for assessing the impact of services upon service receivers including family carers

Religion and Transhumanism Calvin Mercer,Tracy J. Trothen,2014-11-17 Should technology be used to improve human faculties such as cognition and longevity This thought provoking dialogue between transhumanism and religion examines enhancement technologies that could radically alter the human species Transhumanism or human enhancement is an intellectual and cultural movement that advocates the use of emerging technologies to change human traits Although they may sound like science fiction the possibilities suggested by transhumanism are very real and the questions they raise have no easy answers If these enhancements especially major ones like the indefinite extension of healthy human life become widely available they would arguably have a more radical impact on humankind than any other development in history This book comprises essays that explore transhumanism and the issues that surround it addressing numerous fascinating questions posed by scholars of religion from various traditions How will immortality or extreme longevity change our religious beliefs and practices How might pharmaceuticals enhance spiritual experiences Will post human technologies be available to all persons or will a superior post human race arise to dominate the human species The discussions are as intriguing as the future they suggest **Social Work and Disadvantage** Peter Burke,Jonathan Parker,2007 Providing key messages for practice they outline a range of protection measures against disability by association to reduce the risk of stigma and victimisation *Self, Senility, and Alzheimer's Disease in Modern America* Jesse F. Ballenger,2006-03-31 Historian Jesse F Ballenger traces the emergence of senility as a cultural category from the late nineteenth century to the 1980s a period in which Alzheimer s disease became increasingly associated with the terrifying prospect of losing one s self Changes in American society and culture have complicated the notion of selfhood Ballenger finds No longer an ascribed status selfhood must be carefully and willfully constructed Thus losing one s ability to sustain a coherent self narrative is considered one of life s most dreadful losses As Ballenger writes senility haunts the landscape of the self made man Stereotypes of senility and Alzheimer s disease are related to anxiety about the coherence stability and agency of the self stereotypes that are transforming perceptions of old age in modern America Drawing on scientific clinical policy and popular discourses on aging and dementia Ballenger explores early twentieth century concepts of aging and the emergence of gerontology to understand and distinguish normal aging from disease In addition he examines American psychiatry s approaches to the treatment of senility and scientific attempts to understand the brain pathology of dementia Ballenger s work contributes to our understanding of the emergence and significance of dementia as a major health issue Community Series In Mental-Health-Related Stigma and Discrimination: Prevention, Role, and Management Strategies, volume II Renato de Filippis,Mohammadreza Shalbafan,Samer El Hayek,2024-03-06 This Research Topic is the second volume of the Community Series In Mental Health Related Stigma and Discrimination Prevention Role and Management Strategies Please see the first volume here Despite the tremendous progress and successes achieved in diagnostics therapy and rehabilitation in psychiatry over the past few decades the stigma towards mental health patients their relatives and caregivers and healthcare professionals is still present Social stigma in particular represents a major obstacle to maintaining adequate mental health care This increases reluctance to seek help delays patients diagnosis and limits their compliance and adherence to treatment In the long term this reduces psychiatric rehabilitation effectiveness and causes a burden to healthcare providers and society alike The main goal of this Research Topic is to evaluate the impact and role of stigma in all its forms on individuals with psychiatric disorders their caregivers and mental health providers *Nursing Older People* Sally J. Redfern,Fiona Ross,2006 Nursing Older People focuses on evidence based care and the effectiveness of interventions that support independence It takes a person centred approach to understanding and meeting the needs and problems that nurses and other practitioners deal with every day such as the need to reduce the difficulties faced by problems of pain immobility breathlessness eating and drinking and eliminating for example The accessible evidence based information in this book will help to give practitioners the confidence to challenge the status quo and look for ways to improve the quality of care BOOK JACKET **Sociological Abstracts** Leo P. Chall,2003 CSA Sociological Abstracts abstracts and indexes the international literature in sociology and related disciplines in the social and behavioral sciences The database provides abstracts of journal articles and citations to book reviews drawn from over 1 800 serials publications and also provides abstracts of books book chapters dissertations and conference papers **APAIS 1999: Australian public affairs information service** , **Journal of Nervous and Mental Disease** ,1926 July 1918 1943 include reports of various neurological and psychiatric societies Dominant Issues in Medical Sociology Howard D. Schwartz,1994 An updated edition which focuses on the limitations of the sick role The articles consider two major issues in health care organizations the movement from a service to a profit business orientation and prospective payment fixed payment DRGs

Encyclopedia of Aging: Language about aging-psychotherapy ,2002 *Environment and Planning* ,2008 **The British National Bibliography** Arthur James Wells,2006 Families in Society Linda McKie,Sarah Cunningham-Burley,Jo Campling,2005 Acknowledging the increasing diversity and complexity of families this innovative book proposes a new conceptual framework for understanding families and other relationships that both challenges and attempts to reconcile traditional and contemporary approaches Using the notion of boundaries the book shifts thinking from families as entities to families as relationship processes Emphasising the processes that underlie boundary construction and reconstruction suggests that the key to understanding family life is the process of relationship formation The ideas of entity boundary margins and hybridity provide a framework for understanding the diverse and often contradictory ways in which families contribute to society Families in society makes a significant contribution to the academic literature on families and is essential reading for social science students social researchers policy makers and practitioners interested in families and relationships International Journal of Sociology of the Family ,1994 **The Social Construct of the Concept of Dementia and Its Impact on Society** Guadalupe Maria Silva,2017 Objectives To review the historical representations of dementia Background Dementia is a neurodegenerative syndrome affecting over 47 million individuals worldwide and damaging the individualsu2019 cognition and functioning It has an impact on the life of all the people involved in the process of care at the physical psychosocial and economic levels The way individuals perceive dementia has been influenced by socio cultural contexts throughout history and holds different meanings across cultures Methods A literature review was conducted by searching in PubMed database the terms u201cdementia AND history OR society u201d Articles were selected with regard to their scientific relevance Results Early remarks on dementia trace back to classical times when the condition was associated with aging rather than illness This association led to the social construction of the condition as a natural life manifestation and to stigmatising societal views around the process of aging During the Middle Age dementia was a consequence of original sin which led to its association with divine punishment Such construction inevitably leads to stigmatising views with consequences of social withdrawal and exclusion for the person living in the community and the family In the 20th century dementia was classified as organic brain syndrome The emphasis on the scientific diagnosis resulted in the objectification of patients who were reduced to their symptoms or diagnosis regardless of other human characteristics Conclusions Past characterisations of dementia have influenced modern views of the condition The negative views association with aging divine punishment insanity can generate stigma and have negative consequences for individuals with dementia and their family but also for agents involved in the care of dementia A better understanding of the social construction of dementia can improve public health approaches to rehabilitation and care International Review of Modern Sociology ,1996 *Abstracts in Anthropology* ,2003 Quarterly References to journal articles miscellaneous papers and books arranged under sections on archaeology ethnology linguistics and physical anthropology Cross references Cross index **Gentlecare** Moyra Jones,1999 Gentlecare offers a revolutionary new approach to Alzheimer s care Author Moyra Jones sensitive and insightful program for caring for those suffering from dementia emphasizes looking after the whole person body mind and soul She encourages healthcare providers of all kinds to move away from trying to modify behavior and to instead find ways to make the journey through Alzheimer s Disease less traumatic Gentlecare covers every aspect of Alzheimer s caregiving from assessment to attitudes and grooming to communication It looks for ways to cherish the diminishing person and will be of profound interest to anyone affected by Alzheimer s disease whether concerned professionals or family members of those afflicted **American Doctoral Dissertations** ,1994

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