Societal Attitudes towards Older Persons with Dementia:  
Selected Publications and Websites

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German Centre of Gerontology (April 2015)

In March 2015 we conducted an informal literature search regarding the topic “societal attitudes towards older persons with dementia”. In addition we asked the members of the European Research Network COST Action 1402 “Ageism” to provide relevant papers to us. This overview contains three sections.

− First, there is a brief overview on publications (2006 to today). We included empirical studies, reviews, and policy briefs. We got some of the publications as PDF files.
− Secondly, there is an appendix containing links and websites (ordered by countries).
− Thirdly, there is an appendix with the e-mail exchanged (ordered by countries). Here you find more information, also to medical and social care for older people with dementia.

Publications since 2005

Alzheimer Europe. (2013). The ethical issues linked to the perceptions and portrayal of dementia and people with dementia. Luxembourg: Alzheimer Europe. – PDF-Datei des Beitrags


Appendix I: Websites

EU
http://ec.europa.eu/health/mental_health/events/ev_20101108_en.htm
http://ec.europa.eu/health/mental_health/eu_compass/index_en.htm

Bulgaria
Alzheimer Bulgaria Association: http://alzheimer-bg.org
Compassion Alzheimer Bulgaria Foundation: http://www.alzheimerbulgaria.org
ADI - Bulgaria agree to fund dementia medication:
http://www.alz.co.uk/news/bulgaria-agree-to-fund-dementia-medication

Denmark
http://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports

Ireland
Kinsale Community Response to Dementia: http://www.kcord.ie/

Malta
https://sites.google.com/site/maltadementiasociety/

The Netherlands
Interviews with citizens about their image of dementia:
https://www.youtube.com/watch?v=L60rr__f7JI

Poland
Organisationen: http://www.alzheimer-porozumienie.org/tresc-porozumienia/

Portugal
Alzheimer Portugal (Association for Alzheimer Disease): http://alzheimerportugal.org/pt/inicio

Spain
http://www.ceafa.es/es/dependencia
http://fpmaragall.org/
http://www.fafac.cat/?language=es

UK
Alzheimer Society in the UK: http://alzheimers.org.uk/site/index.php
Dementia Services Development Centre (DSDC) http://dementia.stir.ac.uk/
This item from the UK Alzheimer’s society is a good example:
The Scottish Dementia Working Group (SDWG) (national campaigning group, run by people with dementia: http://www.sdwg.org.uk/
Appendix II: Documentation of the E-Mail Exchange

Original Request from Clemens Tesch-Roemer

Dear members of the COST Network 1402 on Ageism,

here is an request from Germany: The German Federal Ministry of Family Affairs, Senior Citizens, Women, and Youth is interested in the topic "(improving) the societal attitudes towards older people with dementia".

It would be very helpful if you could send me a reference or a link (preferably in English) about the situation in your country: Survey results on societal attitudes towards older people with dementia (general population, medical and nursing professionals) or good/best practice examples of how to improve the societal attitudes towards older people with dementia.

Since I do not want to take too much of your time: Please do not invest more than 5-10 minutes in this request. If there is not much response, this would be a result of interest, as well: Topic not treated, yet.

We will document the results and will the results feed back into the COST network. Thank you so much!

Best wishes,

Clemens Tesch-Roemer

EU

Dear Clemens,

I'm not sure this can help, but there is a recent paper from the EU COM on this theme that might provide clues to what you are researching or at least give you some information on the "EU position" on this:


I remember also this conference - more on mental health in general - where the issue of stigma was also addressed (see the background document):

http://ec.europa.eu/health/mental_health/events/ev_20101108_en.htm

This database might have also some good practices examples:
http://ec.europa.eu/health/mental_health/eu_compass/index_en.htm

Best wishes,

Ricardo
Dear Prof. Tesch-Roemer,

I do not work in the field of gerontology, but the dementia problem intrigued me and I tried to look for some information about the situation in Bulgaria.

I found the following civil and governmental organisations concerned with these problems:

Patients’ organisations:
1. Alzheimer Bulgaria Association (http://alzheimer-bg.org)
2. Compassion Alzheimer Bulgaria Foundation (http://www.alzheimerbulgaria.org)
3. Confederation on Health protection

Medical specialist’s organisation:
4. Bulgarian Society on Dementia

Governmental organizations:
5. Ministry of Health
6. Ministry of Labour and Social Policy and
7. Agency for Social Support at the MLSP
8. Agency for people with disabilities at the MLSP

Findings are modest. Although there is some progress in solving problems of vulnerable people with dementia, there are not adequate social policies and services for people suffering from Alzheimer and other dementia illnesses and their families:

There is national consensus on early diagnosis and treatment of Alzheimer’s disease, but not a National program.

There are 14 state homes for people suffering from dementia (capacity of 825 persons), unevenly distributed in the country, most of them do not meet the specific need. No daily centres for people with dementia. Since 2013, the Alzheimer disease is included in the National Health Insurance’s List of medicines for partial reimbursement.) At the end of 2014, the Bulgarian Society of dementia won a grant of 1.5 million euro (in the frame of the Third multiannual program for the health of the EU (2014-2020), which will be invested in medical services for the elderly in all regions of the country.

The Alzheimer Bulgaria Association make some efforts to promote public significance of Alzheimer and other forms of dementia and its inclusion among the priorities of different policies and activities.
Unfortunately, their work is being published in Bulgarian.

Only a few things are available in English - links are below.

1. ADI - Bulgaria agree to fund dementia medication
http://www.alz.co.uk/news/bulgaria-agree-to-fund-dementia-medication
At the end of this page is the UN Report "Concluding observations on the combined fourth and fifth reports of Bulgaria, adopted by the Committee at its fortieth session (12-30 November 2012)".

2. 6th European Patient's Rights Day of the Active Citizenship Network, Brussels
   - Report on Best practices
     Best practice 21 belongs to the Alzheimer Bulgaria Association.

I hope I have been helpful.

At your disposal
with kind regards,
Kamellia

Kamellia Lilova, PhD
Institute for Population and Human Studies - BAS
Acad. G. Bonchev Str., bl. 6, fl. 6, Sofia 1113, Bulgaria
E-mail: ksl@abv.bg

Denmark

Dear Clemens and all

I just want to point you to the 2013 Alzheimer Europe Report: "The ethical issues linked to the perceptions and portrayal of dementia and people with dementia". You can find it here: http://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports
The report is co-authored by Christine Swane, a pioneering Danish researcher in sociocultural dementia research.

Best
Sara Mosberg Iversen
Associate Professor, Department for the Study of Culture
University of Southern Denmark

Germany

Hausner, L., Damian, M., Jekel, K., Richter, M., & Frölich, L. (2012). Einstellungen und Wahrnehmungen zur Demenz-Versorgung in Deutschland. [Attitudes toward dementia management in Germany - Data from the IMPACT survey (Important Perspectives on Alzheimer's
Ireland

Cahill et al give an overview of the Irish dementia landscape in a 2012 review that paved the way for the Irish National Dementia Strategy 2014.

GP attitudes

Public attitudes
Cahill S, O'Shea E, Pierce M. Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy. 2012
see attached Alzheimer's association
Dear Clemens

I would like to introduce you to a community initiative in Ireland: Kinsale Community Response to Dementia (K-CoRD: http://www.kcord.ie/)

I hope that this helps
Alice

Dr Alice Coffey PhD, M.Ed, BA, RGN,RM,RNT.
Director of Globalisation and Internationalisation / College Lecturer
Leader of Healthy Ageing Research Theme
Catherine McAuley School of Nursing and Midwifery
Brookfield Health Sciences Complex
University College Cork
Cork
Ireland

Israel

Hi Clemens

Perla Werner from Israel has done work on this—more on the manifestation side than actual interventions. Here is one link (she has more):

http://psycnet.apa.org/books/14297/012


Abstract
Thousands of others and those around them will be confronted with the consequences of the stigma associated with dementia or Alzheimer’s disease (AD) in the coming decades. These consequences might include discrimination and rejection for the person with AD (Werner, 2005), as well as increased stress and burden for family caregivers (Werner, Mittelman, Goldstein, & Heinik, 2012). Compared with the wealth of studies in the area of stigma and mental illness, especially schizophrenia and depression (Brohan, Slade, Clement, & Thornicroft, 2010), research in the area of AD and stigma is still developing (Werner, 2005). One of the ways to advance understanding in a specific area is to scrutinize and summarize the existing knowledge in order to identify the key characteristics that can guide future research efforts. Therefore, the aim of this chapter is to examine the published literature in the area of stigma and dementia with the objectives of (a) systematically obtaining and evaluating the relevant literature on stigma and dementia and (b) summarizing current research findings and drawing conclusions for future research and interventions in this area. The
The chapter is organized as follows. The evidence emerging from the studies in the review is summarized, and the relevant theoretical frameworks and conceptual issues are described. Methodological issues are addressed, and the chapter concludes with a discussion of the policy and research implications of these findings. (PsycINFO Database Record (c) 2014 APA, all rights reserved)

Best wishes,
Liat

Dear Clemens and all,

I would also like to point you to:


2. There is an ongoing legal study regarding the social construction and attitudes towards dementia within the legal system. Preliminary findings are expected soon.

Yours,
Issi

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**Lithuania**

Dear Clemens,

there are some publications from Lithuania:

Master thesis (Summary in English on p.4)
http://vddb.library.lt/fedora/get/LT-eLABa-0001:E.02~2008~D_20080829_085822-63418/DS.005.0.01.ETD

And if we suppose that society consists of relatives and nurses who are caring for persons with dementia, I believe you can find something useful in these publications as well:


Best regards,
Sarmite from Vilnius


Abstract

Background: Mental health problems are of serious concern across Europe. A major barrier to the realisation of good mental health and well-being is stigma and discrimination. To date there is limited knowledge or understanding of mental health nurses’ attitudes towards mental illness and individuals experiencing mental health problems.

Objectives: To describe and compare attitudes towards mental illness and those experiencing mental health problems across a sample of registered nurses working in mental health settings from five European countries and the factors associated with these attitudes.

Design: A questionnaire survey.

Settings: A total of 72 inpatient wards and units and five community facilities in Finland, Lithuania, Ireland, Italy and Portugal.

Participants: 810 registered nurses working in mental health settings.

Methods: The data were collected using The Community Attitudes towards the Mentally Ill (CAMI) scale, which is a 40-item self-report questionnaire. The data were analysed using quantitative methods.

Results: Nurses’ attitudes were mainly positive. Attitudes differed across countries, with Portuguese nurses’ attitudes being significantly more positive and Lithuanian nurses’ attitudes being significantly more negative than others’. Positive attitudes were associated with being female and having a senior position.

Conclusions: Though European mental health nurses’ attitudes to mental illness and people with mental health problems differ significantly across some countries, they are largely similar. The differences observed could be related to wider social, cultural and organisational circumstances of nursing practice.

Malta

https://sites.google.com/site/maltadementiasociety/
The Netherlands

Dear Clemens,

Your call for research and/or good practices on attitudes towards persons with dementia (see under), was sent to me through age-platform and Prof. Dorly Deeg (Amsterdam). I send you the information I have 'at hand'.

Scientific research, specific on attitudes and images about dementia is lacking in the Netherlands. Qualitative research, ego documents etc. are available, but it is not 'much'. Alzheimer Foundation Netherlands has some qualitative impressions about 'images' on dementia (how patients and informal caregivers 'see' the disease) and finances research to contribute to a positive image of dementia and empowerment of people with dementia.

On social media patients and family write about experiences, indicating the attitudes and prejudice they are confronted with in the case of dementia. Or interviews with citizens about their image of dementia (see for example https://www.youtube.com/watch?v=L60rr__f7JI). Also some books deal with images about dementia (For example 'Leven met dementie van Frans Hoogeveen). The book states that for many people, especially the elderly, dementia is becoming a nightmare: losing your memory, not longer recognising your partner and children, be included in a nursing home. 'You should not think about it.'

Many of the documents say to pay attention to dementia also as a social phenomenon, but in most cases it seems that the disease takes over and the individual disappears. So, the dominant image is often very negative for people with dementia and their environment. People are generally reduced to their condition (with emphasis on the final phase). Research on discrimination against and attitudes towards old persons and growing older is available in the Netherlands, but most research is from some years ago. Research on images about dementia should - in my opinion - by a part of a larger study on chronic, deteriorating diseases, which lead to dependency and death.

If you need more information I could try to find more. When you are looking for Dutch cooperation I would be interested.

Best regards,
Wim

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Summary

Voor veel mensen, vooral ouderen, is dement worden een schrikbeeld. Je geheugen verliezen, op den duur je partner en kinderen niet meer herkennen, opgenomen worden in een verpleeghuis; je moet er niet aan denken. Dementie is misschien ook wel de meest invalidierende ouderdomsziekte, dus het is niet zo gek dat mensen er bang voor zijn. Genezing is nog niet mogelijk. Daarom zullen mensen die eraan lijden ermee moeten leven, net als hun partners en kinderen. Dat is niet gemakkelijk, maar er zijn ondanks alle problemen zeker nog mogelijkheden om er iets van te maken, zo betoogt Frans Hoogeveen, ouderenpsycholoog en auteur van dit boek. Leven met dementie is geschreven voor iedereen die zich wel eens afvraagt of hij of zijn partner dement begint te worden. Maar het boek is vooral bedoeld voor mensen die leven met een partner of familieled die de ziekte al heeft. In heldere taal, met compassie, kennis van zaken én voorbeelden uit de praktijk, legt Frans Hoogeveen uit wat de ziekte inhoudt, welke vormen er zijn en wat het verloop is. Hij besteedt aandacht aan de betekenis van de ziekte voor de betrokkene, de partner en familieleden, en geeft tips voor de omgang met mensen met dementie. Leven met dementie geeft tevens een overzicht van het beschikbare hulp- en informatieaanbod op dit gebied.

Norway

Dear Clemens,

As far as Svein Olav and I know, there is no Norwegian surveys on societal attitudes toward dementia or people suffering from dementia. There are some studies on attitudes among health professionals; Sundaran Kada: “Dementia care quality: A study of health professionals’ attitudes” PhD dissertation University of Bergen 2011. (GPs seems less positive than nursing personnel). In Bergen they also found that nurses with additional education were more positive than nurses with only basic education: Kada S, Nygaard HA, Mukesh BN, Geitung JT. Staff attitudes towards institutionalised dementia residents. J Clin Nurs, 2009;18:2383–92

Best wishes
Per Erik Solem


Summary: The number of individuals with dementia will increase during the coming years due primarily to an increasing number of older people in the population. This will present challenges in relation to how we treat these people, both at home and in institutions. We know that many of them will need care in nursing homes for a shorter or longer period. How will we meet this situation and what are the attitudes and quality found in dementia care? The overall aim of the present thesis was to study the quality and attitudes of health professionals towards persons with dementia and their care. The work is based on three studies. The first study examined the quality and appropriateness of the referrals to specialists. The second study evaluated the quality of the specialists’ reply letters and general practitioners’ satisfaction with the quality of those letters. For both studies the degree to
which the referral and reply letters fulfilled the criteria for the anticipated information content was assessed and a subjective evaluation was made of the quality and appropriateness. The attitudes were assessed indirectly based on this. Both of these studies are based on a total of 135 referrals from the year 2002. The third study evaluated the attitudes of caring staff members in institutions using a questionnaire. The study population was 291 from 14 nursing homes and one geriatric ward in Bergen. In Study I, cognitive and clinical tests were infrequently performed or reported, and key medical information was often absent from the referral letters. There was poor agreement between geriatricians and general practitioners regarding the quality and appropriateness of the referrals. In study II, general practitioners assessed the replies as being of good quality and were satisfied with those letters. However relevant clinical information was missing for a number of patients. In Study III, staff members had an overall positive attitude toward residents with dementia. However there were significant attitudinal differences between staff members with varying levels of education. The indirect interpretation of the findings from both of the first two studies suggests less positive attitudes among general practitioners, something that is supported by international studies. Attitudes among caring staff in nursing homes are generally positive. This indicates that education and information will improve the quality of dementia care and may generate improved attitudes.

Poland

http://www.rpo.gov.pl/sites/default/files/Sytuacja%20os%C3%B3b%20chorych%20na%20choroby%20Alzheimera%20w%20Polsce%20Raport%20RPO.pdf

http://www.alzheimer-porozumienie.org/tresc-porozumienia/

Portugal

Hi Clemens,

In Portugal there is an Association for Alzheimer Disease. It is called “Alzheimer Portugal” (http://alzheimerportugal.org/pt/inicio). It is the most active association in the field of dementia. This association has been fighting for the development of a National Plan for Dementias, similar to the plans which already exist in other European countries.

According to a recent study conducted by the General Directorate of Health (file:///D:/Users/jsjose/Downloads/i021021%20(1).pdf), the proportion of active users of primary health care with the diagnosis of dementia has been growing since 2011. However, this proportion is still very low (below 1% of all users).

Regarding prevalence, there is no reliable data. It is estimated that in Portugal there will be about 160 000 persons with dementia, but the under-diagnosis is a serious problem.

Best wishes, José
Spain

http://www.ceafa.es/es/dependencia
http://fpmaragall.org/
http://www.fafac.cat/?language=es

UK

Dear Clemens,

I suppose that you have already been informed about the The Scottish Dementia Working Group (SDWG) (national campaigning group, run by people with dementia (http://www.sdwg.org.uk/) and similar initiatives in the UK and other countries?

If not, please let me know and I will provide you with more information. I am part of a newly started international research network on Dementia and citizenship where several of the researchers involved are part of these kinds of political initiatives (eg Ruth Bartlett, University of Southampton).

Best regards,
Annika (my e-mail address is not correct in the mailing list, so I did not get your request until now when Andreas forwarded it to me)

Annika Taghizadeh Larsson PhD
Lecturer

A link to the Alzheimer Society in the UK: http://alzheimers.org.uk/site/index.php and to the Dementia Services Development Centre (DSDC) in Scotland with an abundance of good practices http://dementia.stir.ac.uk/

Best regards,
Monika

Dear Clemens,

I hope you will find this paper interesting. It was written by a colleague here at the University of Worcester. There is a growing awareness in the UK of stigma and dementia. This item from the UK Alzheimer’s society is a good example http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=404

All the best, Simon
Dear Clements,

The work of Inthorn and Inthorn is broadly relevant too. Contact details of the authors are on the attached.

Good luck with your study. Your compiled data will be of interest to all.

Kind regards

Maria

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In this paper, we ask how magazines contribute to the public understanding of dementia through their representation of decision-making in response to or anticipation of dementia. We argue that when analyzing the contribution of a particular media form, such as magazines, it is important to pay attention to the ways in which its conventions shape its representational practice. Particularly, we explore representations of dementia in a media form that celebrates the personal and sanctions the public display of emotions. Our argument is based on a quantitative and qualitative analysis of 50 articles, published between January 1, 2013 and August 31, 2013, in three British magazines: Saga Magazine, Yours and Choice. Our findings highlight how popular discourse gives a platform for family members to express the difficulties and emotional dilemmas that making decisions on behalf of
relatives with dementia entails. This suggests that magazines offer a perspective on dementia care that has not yet received much attention in the literature on medical ethics. Medical ethics discusses the process of caretakers balancing different interests but does not explore the emotionality of this process, an emotionality which remains even when decisions have been made and can be rationalized and justified. Our findings suggest that magazines put familial relationships at the heart of dementia care and stress the moral obligation to provide good care, an obligation which seems more important than considerations of autonomy.


This chapter explores the representation of persons with dementia and family caring in Saga Magazine, Yours and Choice, three British magazines aimed at readers aged 50 and above. With a qualitative analysis of 69 articles, published between 1 January 2013 and 30 June 2014, it adds a British case-study to existing work on North American, Australian and Belgian magazines. Similar to these studies, it argues that British magazines deny persons with dementia agency and construct family care as natural duty. In addition, it shows the benefits of considering the conventions of magazines as a media form. Magazines offer a public platform for the expression of emotions. This chapter explores how magazines create a community of interest and empathy that includes those living with dementia, family carers and the wider public. It suggests that British magazines empower carers by offering a space for the emotional experience of care. However, it also shows how an emphasis on emotions can limit carers’ agency. By making care decisions a matter of giving or denying love, British magazines normalise family care as the only ethical solution to the dementia challenge families face.