Research paper

Dementia Stigma Reduction (DESeRvE): Study protocol for a randomized controlled trial of an online intervention program to reduce dementia-related public stigma

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ABSTRACT

Background: Dementia is considered to be a highly stigmatized condition leading to significant negative effects on the health and well-being of people with dementia and people supporting someone living with dementia. Even though there has been an increasing amount of research on dementia-related stigma over the past two decades, research on effective, evidence-based approaches to reduce dementia-related public stigma is still lacking.

Methods: A 2 × 2 factorial randomized controlled trial (RCT) is being conducted to evaluate the feasibility and short-term efficacy of an online intervention program. It compares different approaches to reduce dementia-related public stigma: 1) Education (ED) that is designed to provide written information on dementia; 2) Contact (CT) that is designed to offer indirect virtual contact with people with dementia and/or people supporting someone with dementia; 3) Education plus contact (ED + CT) that is designed to provide both written information on dementia and indirect virtual contact with people with dementia and/or people supporting someone living with dementia; and 4) an active control condition receiving written information on general health. We aim to recruit 500 lay persons aged 40 and over, to complete a questionnaire measuring the level of dementia-related public stigma, assessed with a modified Attribution Questionnaire and dementia knowledge, assessed with the Dementia Knowledge Assessment Scale version 2 at baseline and follow-up assessments (immediately after the intervention and 12 weeks post-intervention).

Discussion: Results from this trial will provide evidence on the most effective approach in reducing dementia-related public stigma. The results are also likely to form an evidence base for the feasibility of dementia-related public stigma campaigns to educate the general public.

1. Introduction

People living with dementia (PWD) and people supporting someone with dementia are often stigmatized, where stigma is defined as an attribute that is deeply discrediting within a social interaction [1], which may lead to labeling, stereotyping, separation, status loss, and discrimination [2]. Dementia-related stigma is due to fear and lack of awareness and understanding about the disease [3]. Dementia-related stigma can cause significant negative effects such as low self-esteem, isolation, poor mental health, decreased quality of life in PWD and increased negative impact of supporting someone with dementia [4–6]. The stigma associated with dementia has been highlighted as the number one concern for people living with the disease and people supporting someone living with dementia worldwide [4,7]. It has also been identified as one of the most important factors contributing to the avoidance of help-seeking behaviors [8,9] therefore, delaying the diagnosis and the utilization of health and social services [10].

There has been a growing amount of research on dementia-related stigma over the past two decades including two recent systematic reviews [11,12] examining different types of stigma: public, family,

professional, courtesy and self/internalized stigma. Consensus of these research was that dementia-related stigma is pervasive, universal and has negative consequences. Stigmatized attitudes exist with both health professionals and the lay public [10]. However, the majority of existing dementia-related stigma research as well as some blogs written by people living with dementia [13,14] has mostly focused on describing the subjective experience of stigma [11]. Evaluating ways of reducing dementia stigmatic beliefs is still lacking. To our knowledge, there is no existing effective data-driven approach to reducing dementia-related public stigma (the stereotypes, prejudice, and discriminatory behaviors held by laypersons toward a person or group with a stigmatized condition) which uses accessible and targeted efficacious interventions. Yet, this is of extreme importance as public stigma has received a great deal of interest in the area of dementia in the past decade [15] and it plays a major role in the formation of other types of stigma such as courtesy stigma (stigma of those associated with a stigmatized person) and self or internalized stigma (prejudice that people with the condition turn against themselves by internalizing the negative attitudes they perceive from society) [16,17].

The two main stigma reduction strategies that are commonly used in other widely studied stigmatized conditions are education and contact [18]. Education involves providing factual information on stigmatizing conditions to replace inaccurate stereotypes and beliefs, and increasing affirming attitudes. Contact involves direct or indirect contact with people with stigmatizing conditions. These approaches however, have not been tested in the area of dementia in the form of an intervention study. Previously conducted research were cross-sectional studies and/or used the experimental vignette methodology to assess the dementia-related stigmatic beliefs of laypersons [19–23]. Of this, only one quantitative study was based on a randomized design [20]. These studies however, suggested that providing education can reduce stigma [12]. Conversely, there has only been one study that found that participation in an intergenerational choir led to a decrease in stigma amongst college students who had interaction with people with dementia or mild cognitive impairment, and their family members [24]. This study may suggest that contact approach can be an effective way of reducing dementia-related public stigma. The effectiveness of personal exposure delivered via online platforms however, has not been investigated in reducing dementia-related public stigma. This RCT therefore, investigates the feasibility and short-term efficacy of an online intervention program, Dementia Risk Reduction (DESeRvE), in public stigma reduction for dementia utilizing different approaches.

2. Methods and analysis

2.1. Study setting and design

The education (ED), contact (CT) and the combination of education and contact (ED + CT) approaches are being compared to an active control group in the 2×2 factorial RCT in dementia-related public stigma reduction. Internet-delivered intervention is being used as it is cost-effective and efficient, and it provides the opportunity for large-scale implementation at the population level compared with more traditional face-to-face interventions [25].

The study is being conducted nationally in Australia. The trial has been designed and is being conducted according to the Consolidated Standards of Reporting Trials (CONSORT) statements for non-pharmaceutical trials [26], and will be reported according to the Standard Protocol Items: Recommendations for Intervention Trials (SPIRIT) guidelines [27]. Dementia Alliance International and Dementia Australia – ACT were on advisory panel for this project.

2.2. Participants

Participants from the general public are currently being recruited by the survey company, Qualtrics (www.qualtrics.com). We aim to recruit

500 participants and follow them for 12 weeks from baseline. There will be two follow up assessments (immediately after the completion of the intervention and at 12 weeks after commencement of the intervention). An invitation email with a link to the DESeRvE has sent to potential participants by Qualtrics. Once the interested participants open the link, an information sheet and a consent form appear before proceeding to the questionnaire. By clicking "I agree", participants confirm that they understand what is provided in the information sheet, that they do meet all inclusion criteria, no exclusion criteria, and that they agree to participate in this trial. Baseline assessment collecting all outcomes and co-variate data has been conducted on the Qualtrics survey platform prior to intervention and primary and secondary outcome data are being collected online again at immediate and 12 weeks follow-ups. Recruitment began in September 2018.

2.3. Inclusion criteria

Participants must be aged 40 years and over, reside in Australia, have access to a computer and internet connection, and be fluent in English.

2.4. Exclusion criteria

Participants are not eligible to enroll in the trial if they are diagnosed with Alzheimer's disease or other types of dementia. They are also ineligible if they have visual and/or auditory deficits with regards to watching video clips.

2.5. Sample size calculations

Sample size calculations were undertaken using G*Power (version 3.1.9.2; http://www.gpower.hhu.de/en.html). To detect a medium effect size, which was based on the previous Body Brain Life (BBL; Trial ID: ACTRN12612000147886) [28,29]) study, in one control and three experimental conditions with a 5% risk of type 1 error (α) and 95% power, a total sample size of 280 persons is required. We are collecting 500 participants at baseline with a 40% dropout rate in mind at the follow-up assessment. This rate was provided by Qualtrics based on their previous experience and statistics on participants coming back for the follow-up assessment.

2.6. Primary outcome

The primary outcome is the general public's level of stigmatic beliefs about people with dementia. It is assessed with an adapted version of the Attribution Questionnaire (AQ) [30], assessing the cognitive, emotional, and behavioral aspects of public stigma in mental illness using three items for each dimension. The term "mental illness" is replaced with the term "dementia" to suit the topic of the current trial and 9-point Likert scale is replaced with a 5 point Likert scale, as a 9-point Likert scale has endpoint anchor labels only and the middle values may have different meanings to different people. An adapted version of the AQ with 9-point Likert scale was used in previous research [15] although this scale was not validated with adult participants. A written vignette describing a person with an early stage of dementia is presented prior to the questionnaire.

2.7. Secondary outcome

The secondary outcome is dementia knowledge which is being assessed with the Dementia Knowledge Assessment Scale (DKAS) - version 2 [31]. This validated and reliable scale comprises of 25 items considered important in understanding dementia and associated care needs.
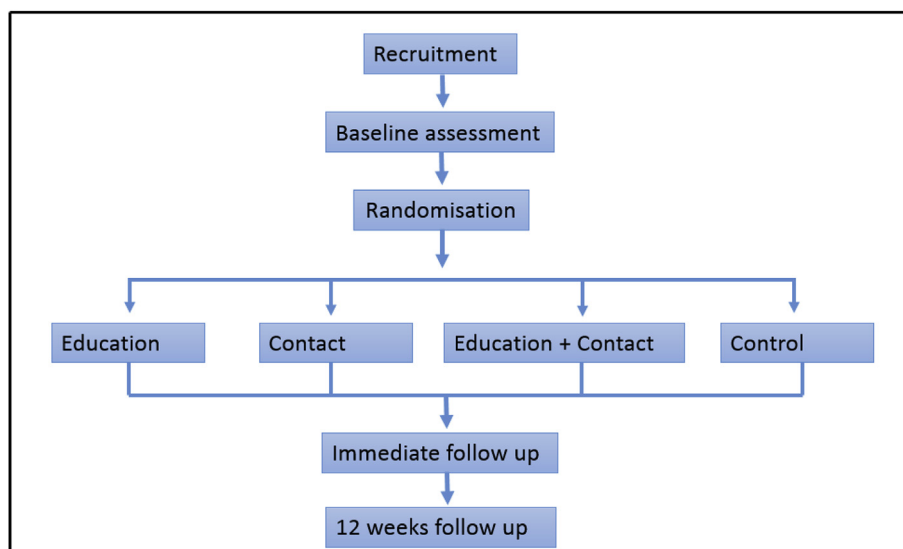
Fig. 1. Study flow.

2.8. Covariate

Sociodemographic information such as gender (male vs female), age (at last birthday), years of education, country of birth (Australia, UK, New Zealand, or others), cultural background (Australian vs others) and weakly household income are being collected. Participants are also being asked if they currently know or had known someone with dementia (yes vs no) and whether they are taking or have taken care of someone with [32]dementia (yes vs no).

2.9. Randomization

Upon completion of the baseline assessment, participants are randomly allocated to one of the four groups (see Fig. 1) using a randomization function on the survey platform (Qualtrics). Randomization is stratified by gender, age and state as previous study [32] suggested that dementia-related stigma is age and gender specific. Randomization by state is undertaken in order to assist with post hoc subgroup analyses as dementia support organizations are state based and interest may develop differently in different state.

Participants are not told explicitly which intervention group they are in. It is likely though, that they are able to infer the group by the introductory notes on the study. Hence blinding cannot be assured.

2.10. Interventions

2.10.1. Group 1: Education (ED)

For the ED group, an adaptation of the dementia literacy module from the BBL is being delivered online. The BBL is the first online intervention program designed to reduce the risk of developing dementia. The dementia literacy module was developed and revised after extensive consumer evaluation by members of the Dementia Australia Consumer Dementia Research Network as well as members of the public and from participant feedback after the previous trial. The module provides information about dementia in terms of definition, symptoms, pathology, and treatments. The BBL is written in laypersons language and is documented to improve dementia literacy in a RCT [29]. Information on dementia-related stigma and its impacts have been added to this module. The education intervention takes approximately 20 min to complete. However, there is no time limit and participants are able to complete the module within a week of starting it. BBL tested feasibility of an online intervention program that utilize both written and visual (video clips) materials to educate the general public.

2.10.2. Group 2: Contact (CT)

Participants in the CT group watch video clips reflecting what it is like to live with dementia and what it is like to care for someone with dementia. These video clips were created featuring people with dementia and people supporting someone living with dementia answering frequently asked questions (FAQ) drawn from a focus group study conducted with 31 mid and older aged Australians [33]. These questions were about dementia and about living with dementia (e.g. what is dementia? How can you best support a person with dementia to maintain independence? How do you manage a person's need to walk freely?). To enhance the effects of the contact component, the DESeRvE program is designed so that participants can choose questions from a pool of questions (FAQ) about what they would like to learn from people with dementia or people supporting someone living with dementia. The program then plays relevant pre-recorded video clips in response to questions. This method is used to make participants feel as if they are having a virtual conversation with a real person with dementia or people supporting someone living with dementia instead of receiving a one-way dialogue. It is expected to be at least as effective as a commonly used video-based contact approach and impact of direct and indirect contact is expected to be equivalent as found in mental health stigma reduction studies [34,35]. The participants can ask as many questions as they wish lasting approximately 20 min. As for the CT group, the CT intervention will be available for a week from the start of the intervention.

2.10.3. Group 3: Education plus Contact (ED + CT)

The ED + CT group receives materials from both CT and ED groups.

2.10.4. Group 4: Active control/email only

The active control group receives written information related to general health. It includes a definition of health, common chronic conditions, risk factors, and health services. It takes approximately 20 min to complete. Participants in this group will have access to materials from education and contact groups as a means of debriefing at the end of the intervention.

2.11. Data management

All data are automatically entered into an SPSS file and stored electronically. These data files are only accessible by the researchers involved in this study.

2.12. Statistical analyses

Descriptive statistics will be calculated for the outcome variables stratified by gender, age and state. A one-way repeated measures analysis of variance will be used to determine the difference between treatment groups over time. In the event of highly correlated responses over time, a longitudinal analysis using multilevel model with random effects will also be fitted to the data. We hypothesize that the level of dementia-related stigma and dementia knowledge will be reduced and enhanced respectively for those in the intervention groups more than those in the Active control group. Intention to treat analysis with multiple imputation of missing values will be used to compare treatment groups.

2.13. Ethics and trial registration

The Human Research Ethics Committee at the Australian National University has approved the study protocols and procedures (protocol #2018/427). This project has also been registered at the Australian New Zealand Clinical Trials Registry (ACTRN: 12618001136291p).

2.14. Adverse events

The target population is adults aged 40 and older who are free of any dementia-related symptoms. We do not anticipate that participants are placed at a greater risk than that associated with self-driven educational activities over the Internet.

2.15. Dissemination plan

Positive, neutral and negative results of the trial will be submitted to international peer-reviewed journals. In addition, results will be presented at national and international conferences relevant to the subject matters. Authorship will be allocated using the guidelines for authorship defined by the International Committees of Medical Journal Editors and will depend on individual involvement.

3. Discussion

Given the negative effects stigma has on people living with dementia, and people supporting someone with dementia as well as on the delivery of timely diagnosis and management, there is a need for an effective program to reduce dementia-related public stigma. This project is currently underway as an evaluation of the short-term efficacy of the Dementia Risk Reduction (DESeRvE) program involving three different approaches, in public stigma reduction for dementia using a RCT. The program also aims to enhance dementia knowledge. We anticipate that all data collection will be completed by December 2018.

The results of the study are likely to form an evidence base for the feasibility of dementia-related stigma campaigns to educate the general public. If successful, DESeRvE can provide a versatile, evidence-based program that can be easily and quickly rolled out in the population. Healthcare providers, workplaces and retirement villages will also be able to use this intervention to educate their clients, employees and residents about dementia and reduce dementia-related stigma. This intervention program will be available to policymakers providing them with a method of reducing dementia-related stigma in areas where it presents a barrier to help-seeking and timely diagnosis and reduces the quality of life. In addition, successful outcomes of the current trial may lead to more people seeking help as soon as they display dementia symptoms, which will have major benefits to individuals and their families.

Disclosure

The authors report no conflicts of interest in this work.

References

[1] E. Goffman, Stigma: Notes on the Management of Spoiled Identity, Prentice Hall, Englewood Cliffs, NJ, 1963.

[2] B.G. Link, J.C. Phelan, Conceptualizing stigma, Annu. Rev. Sociol. 27 (2001) 363–385.

[3] N. Mukadam, G. Livingston, Reducing the stigma associated with dementia: approaches and goals, Aging Health 8 (4) (2012) 377–386.

[4] N.L. Batsch, M.S. Mittelman, World Alzheimer Report 2012: Overcoming the Stigma of Dementia, Alzhaimer's Disease International (ADI), London, UK, 2012.

[5] G. Livingston, C. Cooper, The need for dementia care services, Designing and Delivering Dementia Services, John Wiley & Sons, Ltd, 2013, pp. 3–16.

[6] P. Werner, M.S. Mittelman, D. Goldstein, J. Heinik, Family stigma and caregiver burden in Alzheimer's disease, Gerontol. 52 (1) (2012) 89–97.

[7] Alzheimer's Australia - WA, Dementia Friendly Communities Project: Creating a Dementia Friendly WA, (2015).

[8] M.J.F.J. Vernooij-Dassen, E.D. Moniz-Cook, R.T. Woods, et al., Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma, Int. J. Geriatr. Psychiatry 20 (4) (2005) 377–386.

[9] P. Werner, D. Goldstein, D.S. Karpas, L. Chan, C. Lai, Help-seeking for dementia: a systematic review of the literature, Alzheimers Dis. Assoc. Disord. 28 (4) (2014) 299–310.

[10] L.F. Low, K. Anstey, The public's perception of the plausibility of dementia risk factors is not influenced by scientific evidence, Dement. Geriatr. Cognit. Disord. 23 (3) (2007) 202–206.

[11] P. Werner, Stigma and Alzheimer's disease: a systematic review of evidence, theory, and methods, in: P.W. Corrigan (Ed.), The Stigma of Disease and Disability: Understanding Causes and Overcoming Injustices, American Psychological Association, Washington, DC, US, 2014, pp. 223–244.

[12] L.K. Herrmann, E. Welter, J. Leverenz, et al., A systematic review of dementia-related stigma research: can we move the stigma dial? Am. J. Geriatr. Psychiatry : Off. J. Amer. Assoc. Geriatr. Psych. 26 (3) (2018) 316–331.

[13] K. Swaffer, The real tragedy of dementia. Blog post, Kate Swaffer: Creating Life with Words: Inspiratoration, Love and Truth, 20 June, (2017) Retrieved from https://kateswaffer.com/2017/06/20/the-real-tragedy-of-dementia/2017.

[14] K. Clasper, Time to raise awareness of dementia again, Blog post, Living Well with Lewy Body Dementia, 20 April, 2014 Retrieved from http://ken-kenc2.blogspot.com/2014/04/time-to-raise-awareness-of-dementia.html2014.

[15] P. Werner, H.A. Jabel, Y. Reuveni, D. Prilutzki, Stigmatic beliefs toward a person with Alzheimer's disease among high-school students: does majority–minority status make a difference? Educ. Gerontol. 43 (12) (2017) 609–618.

[16] P.W. Corrigan, A.C. Watson, Understanding the impact of stigma on people with mental illness, World Psychiatr. 1 (1) (2002) 16–20.

[17] P. Werner, J. Heinik, Stigma by association and Alzheimer's disease, Aging Ment. Health 12 (1) (2008) 92–99.

[18] P.W. Corrigan, D.L. Penn, Lessons from social psychology on discrediting psychiatric stigma, Am. Psychol. 54 (1999) 765–776.

[19] R. Johnson, K. Harkins, M. Cary, P. Sankar, J. Karlawish, The relative contributions of disease label and disease prognosis to Alzheimer's stigma: a vignette-based experiment, Soc. Sci. Med. 143 (2015) 117–127.

[20] S. Cheng, L.C.W. Lam, L.C.K. Chan, et al., The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community, Int. Psychogeriatr. 23 (9) (2011) 1433–1441.

[21] S.L. Blay, E.T.P. Peluso, Public stigma: the community's tolerance of Alzheimer disease, Am. J. Geriatr. Psychiatry 18 (2) (2010) 163–171.

[22] M. Cohen, P. Werner, F. Azaiza, Emotional reactions of Arab lay persons to a person with Alzheimer's disease, Aging Ment. Health 13 (1) (2009) 31–37.

[23] P. Werner, Social distance towards a person with Alzheimer's disease, Int. J. Geriatr. Psychiatry 20 (2) (2005) 182–188.

[24] P.B. Harris, C.A. Caporella, An intergenerational choir formed to lessen Alzheimer's disease stigma in college students and decrease the social isolation of people with Alzheimer's disease and their family members: a pilot study, Am. J. Alzheimers Dis. Other Demen. 29 (3) (2014) 270–281.

[25] M.D. Heen, J. Lieberman, T. Miethe, A comparison of different online sampling approaches for generating national samples, Center for Crime and Justice Policy, University of Nevada, Las Vegas USA, 2014.

[26] I. Boutron, D. Moher, D.G. Altman, K.F. Schulz, P. Ravaud, CONSORT Group, Extending the consort statement to randomized trials of nonpharmacologic treatment: explanation and elaboration, Ann. Intern. Med. 148 (4) (2008) 295–309.

[27] A. Chan, J.M. Tetzlaff, D.G. Altman, et al., Spirit 2013 statement: defining standard protocol items for clinical trials, Ann. Intern. Med. 158 (3) (2013) 200–207.

[28] K.J. Anstey, A. Bahar-Fuchs, P. Herath, G.W. Rebok, N. Cherbuin, A 12-week multidomain intervention versus active control to reduce risk of Alzheimer's disease: study protocol for a randomized controlled trial, Trials 14 (2013) 60.

[29] K.J. Anstey, A. Bahar-Fuchs, P. Herath, et al., Body brain life: a randomized

controlled trial of an online dementia risk reduction intervention in middle-aged adults at risk of Alzheimer's disease, Alzheimer's Dementia: Transl. Res. Clin. Interv. 1 (1) (2015) 72–80.

[30] P. Corrigan, F.E. Markowitz, A. Watson, D. Rowan, M.A. Kubiak, An attribution model of public discrimination towards persons with mental illness, J. Health Soc. Behav. 44 (2) (2003) 162–179.

[31] M.J. Annear, C. Toye, K.-E.J. Elliott, F. McInerney, C. Eccleston, A. Robinson, Dementia knowledge assessment scale (DKAS): confirmatory factor analysis and comparative subscale scores among an international cohort, BMC Geriatr. 17 (2017) 168.

[32] S. Kim, M. Mortby, K.J. Anstey. Dementia Stigma and Help Seeking Intentions - A Population Survey from Australia. Unpublished.

[33] S. Kim, P. Werner, A. Richardson, K.J. Anstey, What do the general public really want to know about dementia? A focus group study, Paper Presented at: Alzheimer's Disease International's 33rd Conference 2018; Chicago, USA, 2018.

[34] E. Nguyen, T.F. Chen, C.L. O'Reilly, Evaluating the impact of direct and indirect contact on the mental health stigma of pharmacy students, Soc. Psychiatr. Psychiatr. Epidemiol. 47 (7) (2012) 1087–1098.

[35] X.G. Wang, X.T. Huang, Effectiveness of Direct and Indirect Contact in Reducing Explicit and Implicit Stigma toward Mental Illness, Univ Electronic Science & Technology China Press, Chengdu, 2013.