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BMJ Open

Protocol for a Mixed Methods Study to Understand Needs and Find Solutions For Bereaved Dementia Caregivers

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-086559
Article Type:	Protocol
Date Submitted by the Author:	18-Mar-2024
Complete List of Authors:	Baker, Zachary; Arizona State University O'Donnell, Mary Gemma; Arizona State University Garcia-Arias, Sabrina; Arizona State University Huang, Yingyan; Arizona State University Segundo, Joahana; Arizona State University Millenbah, Ashley N.; Arizona State University Neubert, Olivia; Arizona State University Huerta, Isabel; Arizona State University
Keywords:	Dementia < NEUROLOGY, Caregivers, Family, PALLIATIVE CARE

Protocol for a Mixed Methods Study to Understand Needs and Find Solutions For Bereaved Dementia Caregivers

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Acknowledgments. The authors thank myriad bereaved dementia caregivers who have given their time to first caring for individuals with dementia then to helping the research team understand their experiences so that we might leverage that understanding to improve the lives of future bereaved dementia caregivers.

Abstract

Introduction: Most caregivers of people living with dementia will experience bereavement within 10 years, but study of and support for their needs rarely persists following the death of their care recipients. A single model that leverages theoretical insights as well as observation from lived experience might help identify who will have greater difficulty following dementia-related bereavement and suggest core mechanisms to target to relieve clinical and subclinical consequences. The millions of existing bereaved dementia caregivers likely have considerable insight into ways to improve experience. Rather than creating interventions from scratch, researchers might leverage those insights to more rapidly improve the lives of bereaved dementia caregivers.

Methods and analysis: This study uses a transformative mixed methods approach to explore the needs of caregivers for individuals with Alzheimer's Disease and Related Dementias (AD/ADRD), incorporating both quantitative surveys (n=400) and qualitative semi-structured interviews (n=45) across diverse subgroups. The study described in this protocol aims to quantitatively test a new model based on self-determination theory to help understand when and why bereaved dementia caregivers experience better and worse outcomes following bereavement. The study also aims to qualitatively explore the ways that bereaved dementia caregivers might meet their needs to inform future interventions.

Ethics and dissemination: The study adheres to institutional guidelines, ensuring participant consent and minimizing risks through verbal consent procedures and the removal of personal identifiers from survey responses. The study team will share findings widely through academic publications, conferences, and targeted outreach to advocacy groups and healthcare professionals, while also providing concise summaries of results to participants and making them accessible through the lab's website.

Strengths and Limitations of This Study

- This may be one of the largest studies of bereaved dementia caregivers conducted to date.
- Model development was informed by years of bereaved dementia caregiver observation melded with psychological theory that has been identified as empirically superior when applied to interventions.

- While the model proposes indirect pathways, it will be tested via cross-sectional data.
- The study's recruitment strategy does not ensure that the sample is reflective of the broader population of bereaved dementia caregivers.
- The study will study the adaptive experiences of bereaved dementia caregivers, hopefully speeding the implementation of strategies to improve the lives of other bereaved dementia caregivers.

Introduction

Within 10 years most persons living with Alzheimer's Disease (AD) and AD-Related Dementias (AD/ADRD) will die.[1–3] These deaths mean that most of the 11.48 million current AD/ADRD caregivers will *become bereaved* within 10 years. Upper estimates suggest that 800,000 will die in 2025 in the US with AD (i.e., not including other AD/ADRDs).[4] Given that people living with AD/ADRD have an average of approximately 2 informal caregivers,[1] this means we could have 1.4 million new bereaved AD/ADRD caregivers in the US every year. Many of these caregivers cope with the death of the person with AD/ADRD they cared for without significant disruption to their lives.[5–7] But a sizable proportion of these bereaved AD/ADRD caregivers experience a kind of grief so extreme that domestic (DSM-V-TR) and international (ICD-11) psychological bodies consider it a clinical disorder (i.e., Prolonged Grief Disorder; PGD). Estimates of the prevalence of complicated grief (a condition similar to but not synonymous with PGD) in bereaved AD/ADRD caregivers range from 6-26%.[8] But estimates from the most compelling samples are on the high end of this range at 25%[9] (e.g. Schulz et al., 2006). If these estimates are accurate, there are hundreds of thousands of bereaved AD/ADRD caregivers newly experiencing clinically problematic grief every year. Moreover, even among those who do not develop PGD, a wide range of subclinical consequences can be experienced including increased depressive symptoms, loneliness, and negative affect as well as reduced positive affect, skills/self-care, personal growth, and satisfaction with life.[5,6,8] Promising supports for bereaved AD/ADRD caregivers have been identified[10] (e.g., O'Donnell & Baker, 2023), but understanding of who will have greater or lesser struggles after AD/ADRD deaths is limited.

AD/ADRD refers to the primarily age-related group of progressive neurodegenerative disorders that impair memory and cognitive functioning.[11,12] While, AD makes up a majority of AD/ADRD diagnoses, this set of conditions includes, but is not limited to, Frontotemporal Dementia, Lewy Body Dementia, and Vascular Dementia. Through 2019, AD alone (i.e., not including other AD/ADRDs) ranked as the sixth leading cause of death (fifth for causes of death among older adults). In 2020 and 2021 COVID-19 pushed AD to seventh, but that may mask some AD/ADRD-related deaths because COVID-19 disproportionately killed people living with AD/ADRD.[1] By the year 2050, nearly 13.2 million Americans will have AD/ADRD.[13] There are no curative treatments for AD/ADRD meaning those who develop an AD/ADRD are expected to die with it.[12,14]

Existing Models

Models and research focused on caregiver AD/ADRD-related grief has predominantly explored grief experiences *before* a person living with AD/ADRD dies. For instance, the most recent review of grief in the AD/ADRD care context revealed that quantitative studies of pre-death grief outnumber studies of post-death grief 41:12.[8] To our knowledge, six models attempt to explore or explain AD/ADRD-related grief: four focused on pre-death grief[15–18] and two focused on post-death grief.[19,20]

Post-Death Grief Models

The Two-Track Model of Dementia Grief[20] aims to understand grief as it begins before death and develops after death. This model especially emphasizes the phenomenological experience of grieving as losses mount while a person with AD/ADRD is alive and suggests that the experience after death is especially dependent on the way continuing bonds develop and the story of the person with AD/ADRD's death and illness is integrated into the bereaved AD/ADRD caregiver's personal narrative.

Corey Magan et al. (2020) offered a novel theoretical framework that explained how emotional, coping, and personal and environmental traits impact health outcomes in bereaved AD/ADRD caregivers after the death of an AD/ADRD care recipient. This model is unique compared to the others in its particular focus on experience after death. While, like the other models, and in line with the extant literature, it acknowledges the importance of experience while a person with AD/ADRD is alive, it is particularly concerned with that experience for the ways that it impacts bereaved AD/ADRD caregivers post-death.

Present Model Based on Self-Determination Theory - PATH-BAC

A primary aim of the present study is testing a model to understand which bereaved AD/ADRD caregivers will experience greater clinical and subclinical consequences following bereavement. This model, known as the Post-Caregiving Approach for Tending to Health in Bereaved AD/ADRD Caregivers or "PATH-BAC" is directly informed by self-determination theory[21] and was specifically developed to inform intervention work for bereaved AD/ADRD caregivers. While self-determination theory has been studied in some AD/ADRD contexts,[22,23] it has not, to our knowledge, been used to explore the experiences of bereaved AD/ADRD caregivers. Still, meta-analyses do suggest that while the theory may not systematically result in improved interventions, interventions based on self-determination theory (at least in some contexts) do offer unique benefits over atheoretical counterparts.[24] If valid, PATH-BAC can then be used to inform targeted efforts to reduce those bereavement-related consequences.

Need Satisfaction

PATH-BAC incorporates the importance of basic psychological needs according to self-determination theory, known as autonomy, competence, and relatedness. Crucially, autonomy, competence, and relatedness provide a sound framework for categorizing and understanding AD/ADRD caregivers' needs.[22] Self-determination theory's need satisfaction represents fundamental psychological needs that are essential to the well-being of all people across relationship type, race, sex, and age ("Need Satisfaction" box in Figure 1).[25–27] Autonomy is operationalized as feeling choice and the ability to self-direct behavior, competence represents setting and meeting optimal challenges, and relatedness is reflective of a sense of belonging and having meaningful relationships. These needs can be fulfilled in different ways for different people,[21,28] but the importance of them being fulfilled is common to all people.[21,25] Importantly, the *subjective* experience of having autonomy, competence, and relatedness satisfied is far more important than *objective* perceptions of what will satisfy each need.[29]

Satisfaction of needs for autonomy, competence, and relatedness are hypothesized to benefit bereaved AD/ADRD caregivers in two ways: **1)** through direct decreases in negative outcomes like PGD and increases in positive outcomes like satisfaction and positive affect (Aim 1, Hypothesis 1; path from "Need Satisfaction" to "Clinical and Subclinical Outcomes," Figure 1); and **2)** through changing self-determined motivation for coping, which also decreases negative outcomes and increases positive outcomes (Aim 1; Hypotheses 2&3; path from "Need Satisfaction" to "Self-Determined Motivation for Coping" to "Clinical and Subclinical Outcomes," Figure 1). This motivation reflects coping out of a sense or personal importance or congruence with a sense of self rather than out of internally or externally imposed pressures. For instance, a person whose coping is motivated by a desire to not let down family and friends who expect them to cope with a death would be relatively less self-determined in their motivation for coping. This contrasts with a person whose coping is motivated by an innate desire to continuously grow as a person, for whom motivation is relatively more self-determined.

Self-Determination Theory Constructs in Related Contexts

While there is a lack of study of the role of self-determination theory in bereaved AD/ADRD caregivers, several literatures do point to the potential utility of PATH-BAC. Although need satisfaction causes better outcomes directly, it also improves people's lives through more self-determined motivation ("Self-Determined Motivation for Coping" box in Figure 1).[30,31] More self-determined motivation for caregiving results in a better caregiving experience and a greater sense of well-being.[31–34] These empirical pathways extend beyond relationship type, income, race/ethnicity, age, sex, and culture[21,25,32–36] and are supported in prospective longitudinal studies[33] and interventions[30,37] with caregivers, including two studies in the AD/ADRD care context.[22,3]

Specific Aims

The study described in this protocol is driven by two specific aims. Aim 1 is to quantitatively test PATH-BAC as a means of understanding bereaved AD/ADRD caregiver needs. The primary outcome for this aim is prolonged grief disorder and secondary subclinical outcomes include depressive symptoms, loneliness, negative affect, positive affect, skills/self-care, personal growth, and satisfaction with life. We hypothesize that: Hypothesis 1: Greater need satisfaction will be directly associated with better clinical and subclinical outcomes; Hypothesis 2: More self-determined motivation for coping will be directly associated with better clinical and subclinical outcomes; and Hypothesis 3: Greater need satisfaction will be indirectly related to better clinical and subclinical outcomes through increased self-determined motivation for coping.

Aim 2 is to qualitatively explore how bereaved AD/ADRD caregivers from key subgroups are meeting their needs for autonomy, competence, and relatedness. Given the importance of subjective need satisfaction (see above) spouses, adult children, and extended family will each be interviewed as members of key subgroups to identify need-satisfying experiences that may be amenable to intervention within each subgroup.

Methods and Analysis

This study will use a transformative mixed methods triangular design (citation 47 from grant) to explain the needs of AD/ADRD caregivers among key subgroups (adult children, spouses, other extended family) using a quantitative survey and qualitative semi-structured interview.

Preliminary Work and Patient or Public Involvement

This project is guided by a diverse Community Advisory Board (CAB) of bereaved AD/ADRD caregivers and professionals known as the Supporting Dementia Caregivers After Death CAB. CAB members identify with different races, ethnicities, sexes, genders, ages, clinical specialties, types of dementia, time since bereavement, community organizations, and geographic locations. Specifically, in the K99 pilot phase, these individuals provided input on the type of questions that they felt were important to ask in addition to the proposed measures. This feedback shaped our survey and semi-structured interviews which were then reviewed again by the CAB before we started collecting data. As part of the pilot phase, 24 former dementia caregivers also received a survey or semi structured interview. This pilot phase was key in further modifying our measures for brevity, repetition and overall flow, shaping the measures used in the R00 phase.

Procedures

Before conducting study procedures, staff are trained intensively to become familiar with collecting data over the telephone and entering into REDcap simultaneously. Training also familiarizes staff with the questions they will ask participants, responses they may receive, and learn how to respond appropriately when needed so the participants have the best experience. Training includes: 1.) Reviewing survey or script independently and practice filling it out on their own, 2.) Practice with a family member or friend until comfortable, 3.) Practice via telephone with study coordinators, 4.) Practice via telephone with the PI as if he were an actual participant. Each of these steps may contain multiple iterations until study staff are able to administer materials with proficiency.

We will administer all study materials by phone and responses will be recorded in REDCap. Hard-copy paper versions will be available by request. Participants will first be surveyed and a subsection of those participants will be recontacted to ask if they would like to participate in semi-structured interviews. On average the surveys will take between 60-90 minutes.

Participants will be selected for qualitative semi-structured interviews based on their representation of the key subgroups (spouse, adult child, extended family), diversity in other socio-demographics, and survey scores related to autonomy, confidence, and relatedness. If participants have any difficulty understanding questions or need further encouragement to provide more in-depth responses, probes are included in the interview script. Interviews take approximately 60 minutes and will be audio-recorded and transcribed for analysis.

We have found with both the quantitative survey and qualitative semi-structured interviews that it is important to begin with some background information and conversation to build rapport and trust with participants. This tends to lead to an increased wealth of information, willingness to share, and overall more positive experience for the participant. Because of the nature of the questions being asked and the potential for challenging emotions given the topic of study, we proactively offer resources to each participant following their survey. Resources are housed in our study lab's webpage (https://baker-lab.squarespace.com/supportive-materials) and include emergency hotlines, grief and mental health resources, and book recommendations. Notably, this strategy allows us to a) make materials available without causing participants to feel singled out for having a particularly difficult time and b) constantly update resources as we become aware of new or superior resources.

Participants

Eligible participants were caregivers for a person with any form of AD/ADRD who is now deceased. Eligible bereaved AD/ADRD caregivers will be older than 18 years as well as English-speaking and have the ability to participate in the survey over the phone or via a mailed paper survey. The exclusion criteria for this study include individuals who do not meet the requirements listed above, as well as those currently incarcerated.

For recruitment purposes, we will focus primarily on our network and ties to the community. Some potential ties include but are not limited to, bereaved AD/ADRD caregiver support groups as well as hospice organizations, the Alzheimer's Association, CAB members and their networks, and any other professionals who work in a field that focuses on AD/ADRD care. A recruitment flier was created in the hope that potential participants may be able to easily indicate their interest and gather information regarding the study. Interested individuals will have the option to complete an online form that shares their contact information with the research team. We will also turn to online websites such as Alzheimer's Prevention Registry as well as newsletters to increase reach and awareness of the study with interested community members. Additionally, ResearchMatch.org will be used as a source of recruitment due to its national reach as an electronic, web-based recruitment tool that was first created by the Clinical and Translational Science Awards Consortium back in 2009. ResearchMatch.com is maintained as an IRB-approved data repository. We will also work with our institution's communication teams to pursue news opportunities (e.g., written articles, live or recorded interviews) to inform a broad range of individuals that we are working for bereaved AD/ADRD caregivers and invite them to participate in our research.

After first reaching out to an interested individual, we conduct two follow-up attempts if no response is received. If we do not receive a response after three attempts, we will mark the individual as "not interested" and cease any further contact.

Screening and Imposter Participants

Before scheduling a survey, the research team conducts a thorough screening process to confirm a potential participant meets the initial inclusion criteria and are legitimate bereaved AD/ADRD caregivers. Early efforts suggested that we had to learn how to identify imposter participants to prevent them from participating in the research. Imposter participants are interested individuals who pretend to be bereaved AD/ADRD caregivers in order to receive the $50 to $100 incentive that is offered for participation. We find these individuals join registries (to receive emails about ongoing research) and scan the internet and social media for survey research. In our early administration of the survey, we elected to strategically decide when to stop recruiting from sources that were unknowingly providing a high proportion of imposter participants. Additionally, we have implemented safeguards before talking to potential participants. This includes checking for duplicate IP addresses when someone completes our interest form (a REDcap form attached to our flier, giving us permission to contact them), and checking for suspicious patterns such as duplicate mailing addresses, fake addresses, or phone numbers. We also have a two-step screening process. In the first step, study staff call the potential participant to share details about the study and see if they are a good fit by asking about their prior AD/ADRD care experience by probing into the diagnosis, symptoms, healthcare experience, or general caregiving experience. Often, imposters are unable to provide details whereas real bereaved AD/ADRD caregivers have copious details to spare. If it becomes clear that a person is not a true bereaved AD/ADRD caregiver, we will screen them out before scheduling. If they are scheduled for a survey, the staff member conducting the survey then does their own screening before starting the survey, with similar probes. If they have any suspicions, survey staff are given the autonomy to discontinue a survey at their discretion.

However, once an individual is considered eligible, we will move forward with the consent process prior to starting the survey. Highlights of each section of the consent form will be read and discussed with the participant, allowing opportunities to ask any questions. Once participants feel all of their questions have been answered, the study staff will continue to ask for their verbal consent to continue to participate.

Measures

Quantitative Measures

We aimed to employ survey measures used in the national studies of caregiving and bereavement so that the results from the study can be benchmarked, where possible.

PATH-BAC Elements

The key variables proposed to elucidate mechanistic changes are a) needs satisfaction and b) self-determined motivation for coping.[25,39] Needs satisfaction is assessed via autonomy, competence, and relatedness using the Basic Psychological Needs Satisfaction.[25] We use the Self-Regulation Scale to evaluate self-determined motivation for coping.[39]

Primary and Secondary Outcomes

The primary outcome is prolonged grief disorder evaluated by PG-13-Revised scale.[40] The secondary outcomes include both positive and negative subclinical consequences after AD/ADRD caregiving: depressive symptoms, loneliness, negative/positive affect, ADLs/IADLs, skills/self-care, personal growth, and satisfaction with life.[41–48] We will employ the Eight-Item Shortened Center for Epidemiological Studies Depression Scale to measure the depressive symptoms.[45] Six-Item Revised UCLA Loneliness Scale will be used to measure the loneliness of the bereaved AD/ADRD caregivers.[48] Activities of daily living (ADL) will be evaluated by the Index of ADL[46] and instrumental activities of daily living(IADL) will be assessed using the Lawton IADL Scale.[44] We will implement the Perceived Self-Care and Daily Living Skills to measure skills/self-care.[42] Personal growth will be assessed utilizing the

Posttraumatic Growth Inventory Short Form.[41] Satisfaction with life will be evaluated using the Satisfaction with Life Scale.[43]

Known Risk Factors and Key Covariates

Known risk factors and key covariates for prolonged grief disorder and the associated secondary outcomes include sociodemographics, care partnership characteristics, and coping strategies. Sociodemograhics include race/ethnicity, age, sex, gender, sexual orientation, education and income. Measures for care partnership characteristics include the type of AD/ADRD, time since death, relief at death, recall of pre-loss burden using the 10-Item Short Version of the Burden Scale for Family Caregivers BSFC-s,[49] positive caregiving aspects employing the Positive Aspects of Caregiving measure,[50] person with AD/ADRD residence at death, (In)formal caregiver quality, daily tasks of caregiving using the Resource Utilization in Dementia Instrument,[51] and familial relationship type. The coping strategies include assessments of loss-oriented coping and restoration-oriented coping measured with Dual Coping Inventory,[52] coping self-efficacy assessed with the Coping Competence Scale,[53,54] and caregiving self-efficacy evaluated with the Eight-Item Caregiver Self-Efficacy Scale.[55]

Qualitative Measures

The semi-structured interview aims to expand Dombestein et al.'s (2020) paradigm[56] based on self-determination theory, which will employ lay-person-friendly terms to assess autonomy-, competence-, and relatedness-satisfying experiences among bereaved AD/ADRD caregivers from three key subgroups (i.e., spouses or partners, adult children, extended family). For autonomy, we will ask “ What sorts of things give you a strong sense of choice or freedom in doing what you want to do?” For competence, we may inquire “What makes you feel particularly confident and capable?” For relatedness, we may ascertain “What sorts of things help you feel close and connected to others?” Again, each of these needs also has a series of probes to help convey these constructs without the need for additional probes.

Analysis

A minimum of 400 participants will be enrolled to ensure sufficient statistical power for testing quantitative hypotheses. The calculation of power is informed by estimates of effect size obtained from the largest meta-analysis examining the relationship between need satisfaction/motivation according to self-determination theory and mental and physical health outcomes across various health contexts, which included 184 independent datasets.[57] For hypothesis 1, the association between need satisfaction and psychological/physical health, the meta-analyzed effect sizes suggest a power greater than .99. For hypothesis 2, the association between motivation and psychological/physical health, the expected power is .92. Lastly, for hypothesis 3, the indirect association between need satisfaction and psychological/physical health through self-determined motivation, the anticipated power is .80, a minimum acceptable level often recommended in social science research.[58] This power analysis ensures that the study is appropriately equipped to detect meaningful effects, reducing the risk of Type II errors.

To test hypotheses 1 and 2 with our primary outcome we will regress prolonged grief disorder onto need satisfaction, motivation for coping, and known risk factors/key covariates in a multivariate logistic regression model. The cutoff for statistical significance will be α=.05. Associations will be presented with 95% confidence intervals, unstandardized, and standardized effect sizes to indicate precision and magnitude of associations. To test hypothesis 3, we will specify a structural equation model that is identical to the regression specified above with the additional path of self-determined motivation regressed onto need satisfaction. The statistical significance cutoff will be a confidence interval that does not include zero. Indirect associations will be estimated through bootstrapping and presented with a 95% confidence interval, unstandardized, and standardized effect sizes.

Drawing from the overall sample, we will use the demographic information collected in the quantitative survey to identify bereaved AD/ADRD caregivers for qualitative semi-structured interviews. Participants will fall into one of three categories: a) spouses, b) adult-children, and c) extended family. We aim to recruit a total of 36-45 participants,12-15 from each of these categories. Our recruitment strategy will emphasize diversity within each of these relationship categories. We will consider factors including need satisfaction scores, race, ethnicity, gender, and age when selecting participants. This approach will enable us to gather insights from a wide range of perspectives. Additionally, the number of interviews that will be conducted aligns with an iterative inductive methodology,[59,60] allowing us to delve deeper into groups that provide distinct responses during the interview process.

We will explore experiences of need satisfaction through partially deductive systematic text condensation thematic analysis[61,62] in four steps: 1) total impression, 2) identifying and sorting by codes, 3) condensation from coding to meaning, 4) synthesizing information. We will hierarchically organize domains and experiences that provide need satisfaction to participants using self-determination theory's perspective. Themes will be organized by the referenced need (autonomy, competence, relatedness), and who feels that the experience affects their needs (adult children, spouses, extended family). We are interested in the ways that need satisfying experiences align or diverge between subgroups of bereaved AD/ADRD caregivers. This strategy is considered partially *deductive* because the categories are driven by self-determination theory.[60] This strategy is partially *inductive* because it allows for new needs to emerge.[60] We will further explore whether need satisfaction sources differ within key subgroups by race/ethnicity and sex and will purposively sample additional members of those groups when answers differ.

Data

In compliance with the National Institutes of Health's data sharing rules, we will provide access to the final quantitative dataset and related documentation to other users via a data repository. Access to data will require a commitment to: use the data exclusively for research purposes; ensure no individual participant can be identified (although the data will be de-identified, there is still a small risk of deducing identities based on unique characteristics); and employ adequate data security measures.

Ethics and Informed Consent

Arizona State University Institutional Review Board (STUDY00016256) gave expedited approval and supervises the study in alignment with requirements from the National Institutes of Health. Verbal consent is obtained from the bereaved AD/ADRD caregivers before proceeding with the surveys and interviews. During the pilot K99 phase, consent was achieved with a full consent form. To reduce participant burden, in line with direct participant feedback, changes were made to obtain consent verbally via telephone script. Signatures were also removed in consideration of participant risk in order to remove the link between personal information and survey responses. Modifications made during the R00 phase allow consent to be given to study staff based upon a shortened consent script as the project does not require full IRB review due to there being no greater than minimal risk to participants. In the script, highlights of the study are reviewed and the potential participant is iteratively asked for questions. This script is read to bereaved AD/ADRD caregivers at the beginning of both quantitative and qualitative components. The participant is then asked for approval for continued contact in future research projects. Participants are notified that approval is not required for participation in the current research. Additionally, participants are notified that resources for bereaved AD/ARD caregivers are available. Resources can be accessed via telephone during the interview and after by means of the Former Dementia Care Lab website.

Dissemination

We intend to disseminate the study's results via journal publications in gerontology journals and conferences. The results of this study are crucial to disseminate to advocacy organizations and healthcare professionals as a way to inform future interventions that aim to reduce the clinical and subclinical consequences of bereavement.

To all participants who approved further communication from the lab, a one-page concise explanation of the results will be sent via email along with a link to access the published findings. These one-page documents will be developed by the research team, shared with the CAB, and edited in accordance with their feedback prior to sharing with participants. We will then also host these documents on our lab website so that they are available to any interested individuals in the future. A unique one page document will be created for each publication in an academic journal.

Discussion

This study's aims use PATH-BAC, based on self-determination theory to understand the needs of bereaved AD/ADRD caregivers while accounting for the differences in the ways those needs are satisfied among key subgroups. The study also aims to qualitatively identify ways that bereaved AD/ADRD caregivers are already meeting their needs so that those strategies may be shared with other bereaved AD/ADRD caregivers who may be struggling. The wider goal of this research is to use the understanding of bereaved AD/ADRD caregivers' needs to create interventions to satisfy those needs, reducing the clinical and subclinical consequences of bereavement.

The focus on autonomy, competence, and relatedness provides flexibility in understanding and addressing diverse needs among bereaved AD/ADRD caregivers.

This framework allows for a nuanced exploration of their experiences, which can be broadly applied. For example, in the context of the need for autonomy, adult child caregivers might be satisfied with newfound free time, while spousal caregivers may feel paralyzed by it. In this way, the same experience is subjectively very different, allowing researchers to better conceptualize bereaved AD/ADRD caregivers' phenomenological experience. Likewise, the needs for competence and relatedness are common to all caregivers[56] but may be satisfied in different ways for different kinds of bereaved AD/ADRD caregivers.

The proposed research is innovative in its focus on key subgroups, application of self-determination theory, and employment of a diverse CAB focused on bereaved AD/ADRD caregivers. Bereaved AD/ADRD caregivers are at elevated risk for clinically pathological and subclinically problematic consequences and their numbers are increasing quickly. The work will address the National Institute on Aging's goal to increase understanding of bereaved AD/ADRD caregivers' needs, informing future interventions that reduce the clinical and subclinical consequences of bereavement.

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Authors' Contributions

ZGB led the conception, design, and execution of the study, assuming the role of principal investigator for the project. JS and ANM, facilitated resource management, team mentorship, data curation, visualization, and supervision of the study. JS provided software support. JS, ANM, MGO, SGA, JS, OMN, IH, contributed to writing, review, and editing of the original manuscript. ANM and JS supplied protocol development and modification. All authors provided approval for the protocol to be published.

Competing Interests

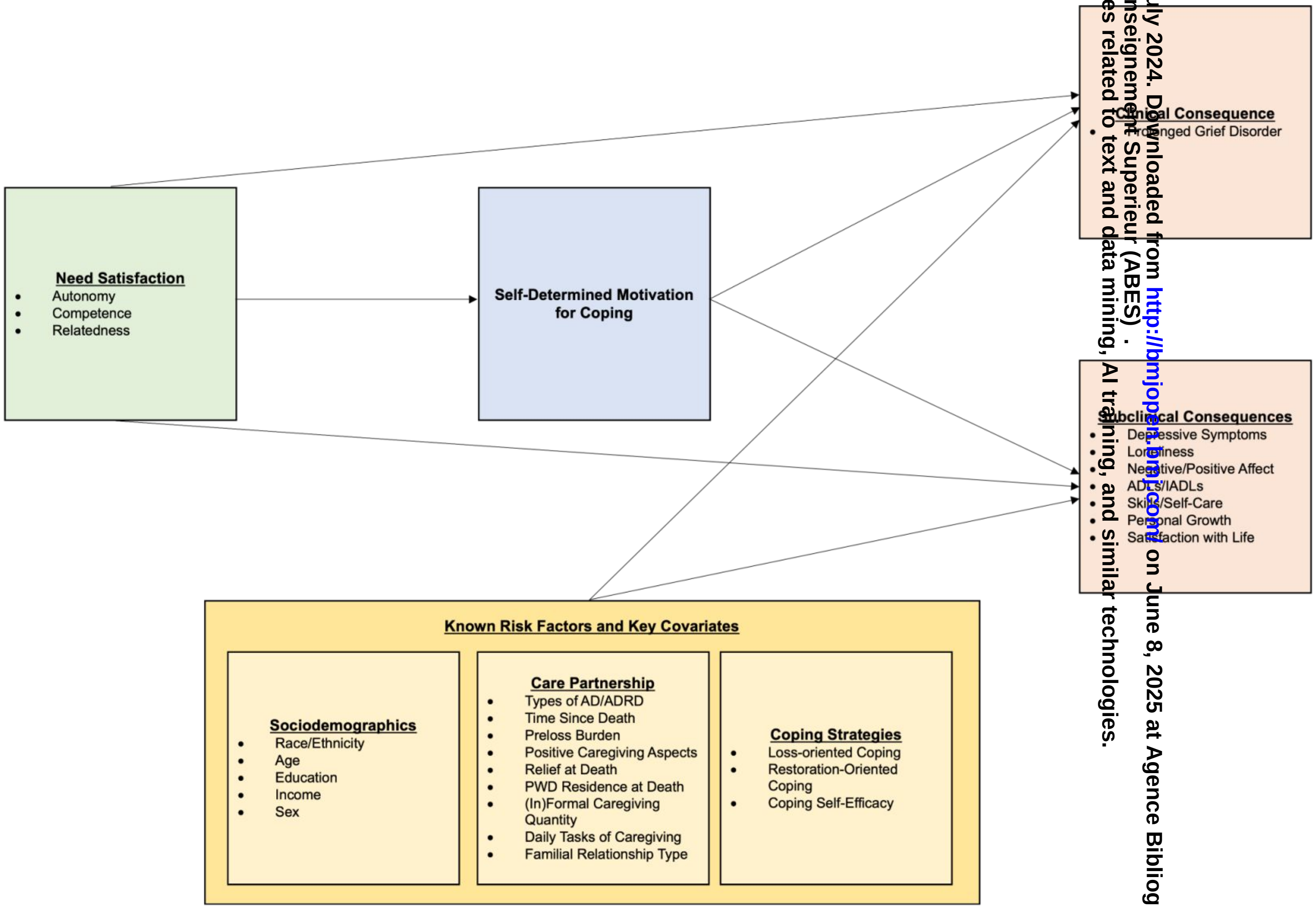
The authors have no competing interests.

Funding Statement

Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under Award Numbers R00AG073463. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Figure 1

Post-Caregiving Approach for Tending to Health in Bereaved AD/ADRD Caregivers (PATH-BAC) Model



BMJ Open

Protocol for a Telephonic Mixed Methods Study to Understand Needs and Find Solutions For Bereaved Dementia Caregivers

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-086559.R1
Article Type:	Protocol
Date Submitted by the Author:	21-May-2024
Complete List of Authors:	Baker, Zachary; Arizona State University O'Donnell, Mary Gemma; Arizona State University Garcia-Arias, Sabrina; Arizona State University Huang, Yingyan; Arizona State University Segundo, Joahana; Arizona State University Millenbah, Ashley N.; Arizona State University Neubert, Olivia; Arizona State University Huerta, Isabel; Arizona State University
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Palliative care
Keywords:	Dementia < NEUROLOGY, Caregivers, Family, PALLIATIVE CARE

Protocol for a Telephonic Mixed Methods Study to Understand Needs and Find Solutions For Bereaved Dementia Caregivers

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Acknowledgments. The authors thank myriad bereaved dementia caregivers who have given their time to first caring for individuals with dementia then to helping the research team understand their experiences so that we might leverage that understanding to improve the lives of future bereaved dementia caregivers.

Abstract

Introduction: Most caregivers of people living with dementia will experience bereavement within 10 years, but study of and support for their needs rarely persists following the death of their care recipients. A single model that leverages theoretical insights as well as observation from lived experience might help identify who will have greater difficulty following dementia-related bereavement and suggest core mechanisms to target to relieve clinical and subclinical consequences. The millions of existing bereaved dementia caregivers likely have considerable insight into ways to improve experience. Rather than creating interventions from scratch, researchers might leverage those insights to more rapidly improve the lives of bereaved dementia caregivers.

Methods and analysis: This study uses a transformative mixed methods approach to explore the needs of caregivers for individuals with Alzheimer's Disease and Related Dementias (AD/ADRD), incorporating both quantitative surveys (n=400) and qualitative semi-structured interviews (n=45) across diverse subgroups. The study described in this protocol aims to quantitatively test a new model based on self-determination theory to

help understand when and why bereaved dementia caregivers experience better and worse outcomes following bereavement. The study also aims to qualitatively explore the ways that bereaved dementia caregivers might meet their needs to inform future interventions.

Ethics and dissemination: The study adheres to institutional guidelines, ensuring participant consent and minimizing risks through verbal consent procedures and the removal of personal identifiers from survey responses. The study team will share findings widely through academic publications, conferences, and targeted outreach to advocacy groups and healthcare professionals, while also providing concise summaries of results to participants and making them accessible through the lab's website.

Strengths and Limitations of This Study

- This remotely conducted study will engage bereaved dementia caregivers across the country including in rural locales.
- Model development was informed by years of bereaved dementia caregiver observation melded with psychological theory that has been identified as empirically superior when applied to interventions.

- While the model proposes indirect pathways, it will be tested via cross-sectional data.
- The study's recruitment strategy does not ensure that the sample is reflective of the broader population of bereaved dementia caregivers.

Introduction

Within 10 years most persons living with Alzheimer's Disease (AD) and AD-Related Dementias (AD/ADRD) will die.[1–3] These deaths mean that most of the 11.48 million current AD/ADRD caregivers will *become bereaved* within 10 years. Upper estimates suggest that 800,000 will die in 2025 in the US with AD (i.e., not including other AD/ADRDs).[4] Given that people living with AD/ADRD have an average of approximately 2 informal caregivers,[1] this means we could have 1.4 million new bereaved AD/ADRD caregivers in the US every year. Many of these caregivers cope with the death of the person with AD/ADRD they cared for without significant disruption to their lives.[5-7] But a sizable proportion of these bereaved AD/ADRD caregivers experience a kind of grief so extreme that domestic (DSM-V-TR) and international (ICD-11) psychological bodies consider it a clinical disorder (i.e., Prolonged Grief Disorder; PGD). Estimates of the prevalence of complicated grief (a condition similar to but not synonymous with PGD) in bereaved AD/ADRD caregivers range from 6-26%.[8] But estimates from the most compelling samples are on the high end of this range at 25%[9] (e.g. Schulz et al., 2006). If these estimates are accurate, there are hundreds of thousands of bereaved AD/ADRD caregivers newly experiencing clinically problematic grief every year. Moreover, even among those who do not develop PGD, a wide range of subclinical consequences can be experienced including increased depressive symptoms, loneliness, and negative affect as well as reduced positive affect, skills/self-care, personal growth, and satisfaction with life.[5,6,8] Promising supports for bereaved

AD/ADRD caregivers have been identified[10], but understanding of who will have greater or lesser struggles after AD/ADRD deaths is limited.

AD/ADRD refers to the primarily age-related group of progressive neurodegenerative disorders that impair memory and cognitive functioning.[11,12] While, AD makes up a majority of AD/ADRD diagnoses, this set of conditions includes, but is not limited to, Frontotemporal Dementia, Lewy Body Dementia, and Vascular Dementia. Through 2019, AD alone (i.e., not including other AD/ADRDs) ranked as the sixth leading cause of death (fifth for causes of death among older adults). In 2020 and 2021 COVID-19 pushed AD to seventh, but that may mask some AD/ADRD-related deaths because COVID-19 disproportionately killed people living with AD/ADRD.[1] By the year 2050, nearly 13.2 million Americans will have AD/ADRD.[13] There are no curative treatments for AD/ADRD meaning those who develop an AD/ADRD are expected to die with it.[12,14]

Existing Models

Models and research focused on caregiver AD/ADRD-related grief has predominantly explored grief experiences *before* a person living with AD/ADRD dies. For instance, the most recent review of grief in the AD/ADRD care context revealed that quantitative studies of pre-death grief outnumber studies of post-death grief 41:12.[8] To our knowledge, six models attempt to explore or explain AD/ADRD-related grief: four focused on pre-death grief[15-18] and two focused on post-death grief.[19,20]

Post-Death Grief Models

The Two-Track Model of Dementia Grief[20] aims to understand grief as it begins before death and develops after death. This model especially emphasizes the phenomenological experience of grieving as losses mount while a person with AD/ADRD is alive and suggests that the experience after death is especially dependent on the way continuing bonds develop and the story of the person with AD/ADRD's death and illness is integrated into the bereaved AD/ADRD caregiver's personal narrative.

Corey Magan et al. (2020) offered a novel theoretical framework that explained how emotional, coping, and personal and environmental traits impact health outcomes in bereaved AD/ADRD caregivers after the death of an AD/ADRD care recipient. This model is unique compared to the others in its particular focus on experience after death. While, like the other models, and in line with the extant literature, it acknowledges the importance of experience while a person with AD/ADRD is alive, it is particularly concerned with that experience for the ways that it impacts bereaved AD/ADRD caregivers post-death.

Present Model Based on Self-Determination Theory - PATH-BAC

A primary aim of the present study is testing a model to understand which bereaved AD/ADRD caregivers will experience greater clinical and subclinical consequences following bereavement. This model, known as the Post-Caregiving Approach for Tending to Health in Bereaved AD/ADRD Caregivers or "PATH-BAC" is directly informed by self-determination theory[21] and was specifically developed to inform intervention work for bereaved AD/ADRD caregivers. While self-determination theory has been studied in some AD/ADRD contexts,[22,23] it has not, to our knowledge, been used to explore the experiences of bereaved AD/ADRD caregivers. Still, meta-analyses do suggest that while the theory may not systematically result in improved interventions, interventions based on self-determination theory (at least in some contexts) do offer unique benefits over atheoretical counterparts.[24] If valid, PATH-BAC can then be used to inform targeted efforts to reduce those bereavement-related consequences.

Need Satisfaction

PATH-BAC incorporates the importance of basic psychological needs according to self-determination theory, known as autonomy, competence, and relatedness. Crucially, autonomy, competence, and relatedness provide a sound framework for categorizing and understanding AD/ADRD caregivers' needs.[22] Self-determination theory's need satisfaction represents fundamental psychological needs that are essential to the well-being of all people across relationship type, race, sex, and age ("Need Satisfaction" box in Figure 1).[25-27] Autonomy is operationalized as feeling choice and the ability to self-direct behavior, competence represents setting and meeting optimal challenges, and relatedness is reflective of a sense of belonging and having meaningful relationships. These needs can be fulfilled in different ways for different people,[21,28] but the importance of them being fulfilled is common to all people.[21,25] Importantly, the *subjective* experience of having autonomy, competence, and relatedness satisfied is far more important than *objective* perceptions of what will satisfy each need.[29]

Satisfaction of needs for autonomy, competence, and relatedness are hypothesized to benefit bereaved AD/ADRD caregivers in two ways: **1)** through direct decreases in negative outcomes like PGD and increases in positive outcomes like satisfaction and positive affect (Aim 1, Hypothesis 1; path from “Need Satisfaction” to “Clinical and Subclinical Outcomes,” Figure 1); and **2)** through changing self-determined motivation for coping, which also decreases negative outcomes and increases positive outcomes (Aim 1; Hypotheses 2&3; path from “Need Satisfaction” to “Self-Determined Motivation for Coping” to “Clinical and Subclinical Outcomes,” Figure 1). This motivation reflects coping out of a sense or personal importance or congruence with a sense of self rather than out of internally or externally imposed pressures. For instance, a person whose coping is motivated by a desire to not let down family and friends who expect them to cope with a death would be relatively less self-determined in their motivation for coping. This contrasts with a person whose coping is motivated by an innate desire to continuously grow as a person, for whom motivation is relatively more self-determined.

Self-Determination Theory Constructs in Related Contexts

While there is a lack of study of the role of self-determination theory in bereaved AD/ADRD caregivers, several literatures do point to the potential utility of PATH-BAC. Although need satisfaction causes better outcomes directly, it also improves people’s lives through more self-determined motivation (“Self-Determined Motivation for Coping” box in Figure 1).[30,31] More self-determined motivation for caregiving results in a better caregiving experience and a greater sense of well-being.[31-34] These empirical pathways extend beyond relationship type, income, race/ethnicity, age, sex, and culture[21,25,32-36] and are supported in prospective longitudinal studies[33] and interventions[30,37] with caregivers, including two studies in the AD/ADRD care context.[22,38]

Specific Aims

The study described in this protocol is driven by two specific aims. Aim 1 is to quantitatively test PATH-BAC as a means of understanding bereaved AD/ADRD caregiver needs. The primary outcome for this aim is prolonged grief disorder and secondary subclinical outcomes include depressive symptoms, loneliness, negative affect, positive affect, skills/self-care, personal growth, and satisfaction with life. We hypothesize that: Hypothesis 1: Greater need satisfaction will be directly associated with better clinical and subclinical outcomes; Hypothesis 2: More self-determined motivation for coping will be directly associated with better clinical and subclinical outcomes; and Hypothesis 3: Greater need satisfaction will be indirectly related to better clinical and subclinical outcomes through increased self-determined motivation for coping.

Aim 2 is to qualitatively explore how bereaved AD/ADRD caregivers from key subgroups are meeting their needs for autonomy, competence, and relatedness. Given the importance of subjective need satisfaction (see above) spouses, adult children, and extended family will each be interviewed as members of key subgroups to identify need-satisfying experiences that may be amenable to intervention within each subgroup.

Methods and Analysis

This study will use a transformative mixed methods triangular design (citation 47 from grant) to explain the needs of AD/ADRD caregivers among key subgroups (adult children, spouses, other extended family) using a quantitative survey and qualitative semi-structured interview. The study will be conducted in the United States from March 2023 – December 2024.

Procedures

Before conducting study procedures, staff are trained intensively to become familiar with collecting data over the telephone and entering into REDcap simultaneously. Training also familiarizes staff with the questions they will ask participants, responses they may receive, and learn how to respond appropriately when needed so the participants have the best experience. Training includes: 1.) Reviewing survey or script independently and practice filling it out on their own, 2.) Practice with a family member or friend until comfortable, 3.) Practice via telephone with study coordinators, 4.) Practice via telephone with the PI as if he were an actual participant. Each of these steps may contain multiple iterations until study staff are able to administer materials with proficiency.

We will administer all study materials by phone and responses will be recorded in REDCap. Hard-copy paper versions will be available by request. Participants will first be surveyed and a subsection of those participants will be recontacted to ask if they would like to participate in semi-structured interviews. On average the surveys will take between 60-90 minutes.

Participants will be selected for qualitative semi-structured interviews based on their representation of the key subgroups (spouse, adult child, extended family), diversity in other socio-demographics, and survey scores related to autonomy, confidence, and relatedness. If participants have any difficulty understanding questions or need further encouragement to provide more in-depth responses, probes are included in the interview script. Interviews take approximately 60 minutes and will be audio-recorded and transcribed for analysis.

We have found with both the quantitative survey and qualitative semi-structured interviews that it is important to begin with some background information and conversation to build rapport and trust with participants. This tends to lead to an increased wealth of information, willingness to share, and overall more positive experience for the participant. Because of the nature of the questions being asked and the potential for challenging emotions given the topic of study, we proactively offer resources to each participant following their survey. Resources are housed in our study lab's webpage (https://baker-lab.squarespace.com/supportive-materials) and include emergency hotlines, grief and mental health resources, and book recommendations. Notably, this strategy allows us to a) make materials available without causing participants to feel singled out for having a particularly difficult time and b) constantly update resources as we become aware of new or superior resources.

Participants

Eligible participants were caregivers for a person with any form of AD/ADRD who is now deceased. Eligible bereaved AD/ADRD caregivers will be older than 18 years as well as English-speaking and have the ability to participate in the survey over the phone or via a mailed paper survey. The exclusion criteria for this study include individuals who do not meet the requirements listed above, as well as those currently incarcerated.

For recruitment purposes, we will focus primarily on our network and ties to the community. Some potential ties include but are not limited to, bereaved AD/ADRD caregiver support groups as well as hospice organizations, the Alzheimer's Association, CAB members and their networks, and any other professionals who work in a field that focuses on AD/ADRD care. A recruitment flier was created in the hope that potential participants may be able to easily indicate their interest and gather information regarding the study. Interested individuals will have the option to complete an online form that shares their contact information with the research team. We will also turn to online websites such as Alzheimer's Prevention Registry as well as newsletters to increase reach and awareness of the study with interested community members. Additionally, ResearchMatch.org will be used as a source of recruitment due to its national reach as an electronic, web-based recruitment tool that was first created by the Clinical and Translational Science Awards Consortium back in 2009. ResearchMatch.com is maintained as an IRB-approved data repository. We will also work with our institution's communication teams to pursue news opportunities (e.g., written articles, live or recorded interviews) to inform a broad range of individuals that we are working for bereaved AD/ADRD caregivers and invite them to participate in our research.

After first reaching out to an interested individual, we conduct two follow-up attempts if no response is received. If we do not receive a response after three attempts, we will mark the individual as “not interested” and cease any further contact.

Screening and Imposter Participants

Before scheduling a survey, the research team conducts a thorough screening process to confirm a potential participant meets the initial inclusion criteria and are legitimate bereaved AD/ADRD caregivers. Early efforts suggested that we had to learn how to identify imposter participants to prevent them from participating in the research. Imposter participants are interested individuals who pretend to be bereaved AD/ADRD caregivers in order to receive the $50 to $100 incentive that is offered for participation. We find these individuals join registries (to receive emails about ongoing research) and scan the internet and social media for survey research. In our early administration of the survey, we elected to strategically decide when to stop recruiting from sources that were unknowingly providing a high proportion of imposter participants. Additionally, we have implemented safeguards before talking to potential participants. This includes checking for duplicate IP addresses when someone completes our interest form (a REDcap form attached to our flier, giving us permission to contact them), and checking for suspicious patterns such as duplicate mailing addresses, fake addresses, or phone numbers. We also have a two-step screening process. In the first step, study staff call the potential participant to share details about the study and see if they are a good fit by asking about their prior AD/ADRD care experience by probing into the diagnosis, symptoms, healthcare experience, or general caregiving experience. Often, imposters are unable to provide details whereas real bereaved AD/ADRD caregivers have copious details to spare. If it becomes clear that a person is not a true bereaved AD/ADRD caregiver, we will screen them out before scheduling. If they are scheduled for a survey, the staff member conducting the survey then does their own screening before starting the survey, with similar probes. If they have any suspicions, survey staff are given the autonomy to discontinue a survey at their discretion.

However, once an individual is considered eligible, we will move forward with the consent process prior to starting the survey. Highlights of each section of the consent form will be read and discussed with the participant, allowing opportunities to ask any questions. Once participants feel all of their questions have been answered, the study staff will continue to ask for their verbal consent to continue to participate.

Measures

Quantitative Measures

We aimed to employ survey measures used in the national studies of caregiving and bereavement so that the results from the study can be benchmarked, where possible.

PATH-BAC Elements

The key variables proposed to elucidate mechanistic changes are a) needs satisfaction and b) self-determined motivation for coping.[25,39] Needs satisfaction is assessed via autonomy, competence, and relatedness using the Basic Psychological

Needs Satisfaction.[25] We use the Self-Regulation Scale to evaluate self-determined motivation for coping.[39]

Primary and Secondary Outcomes

The primary outcome is prolonged grief disorder evaluated by PG-13-Revised scale.[40] The secondary outcomes include both positive and negative subclinical consequences after AD/ADRD caregiving: depressive symptoms, loneliness, negative/positive affect, ADLs/IADLs, skills/self-care, personal growth, and satisfaction with life.[41-48] We will employ the Eight-Item Shortened Center for Epidemiological Studies Depression Scale to measure the depressive symptoms.[45] Six-Item Revised UCLA Loneliness Scale will be used to measure the loneliness of the bereaved AD/ADRD caregivers.[48] Activities of daily living (ADL) will be evaluated by the Index of ADL[46] and instrumental activities of daily living(IADL) will be assessed using the Lawton IADL Scale.[44] We will implement the Perceived Self-Care and Daily Living Skills to measure skills/self-care.[42] Personal growth will be assessed utilizing the Posttraumatic Growth Inventory Short Form.[41] Satisfaction with life will be evaluated using the Satisfaction with Life Scale.[43]

Known Risk Factors and Key Covariates

Known risk factors and key covariates for prolonged grief disorder and the associated secondary outcomes include sociodemographics, care partnership characteristics, and coping strategies. Sociodemograhics include race/ethnicity, age, sex, gender, sexual orientation, education and income. Measures for care partnership characteristics include the type of AD/ADRD, time since death, relief at death, recall of pre-loss burden using the 10-Item Short Version of the Burden Scale for Family Caregivers BSFC-s,[49] positive caregiving aspects employing the Positive Aspects of Caregiving measure,[50] person with AD/ADRD residence at death, (In)formal caregiver quality, daily tasks of caregiving using the Resource Utilization in Dementia Instrument,[51] and familial relationship type. The coping strategies include assessments of loss-oriented coping and restoration-oriented coping measured with Dual Coping Inventory,[52] coping self-efficacy assessed with the Coping Competence Scale,[53,54] and caregiving self-efficacy evaluated with the Eight-Item Caregiver Self-Efficacy Scale.[55]

Qualitative Measures

The semi-structured interview (please see supplemental materials) aims to expand Dombestein et al.'s (2020) paradigm[56] based on self-determination theory, which will employ lay-person-friendly terms to assess autonomy-, competence-, and relatedness-satisfying experiences among bereaved AD/ADRD caregivers from three key subgroups (i.e., spouses or partners, adult children, extended family). For autonomy, we will ask " What sorts of things give you a strong sense of choice or freedom in doing what you want to do?" For competence, we may inquire "What makes you feel particularly confident and capable?" For relatedness, we may ascertain "What sorts of things help you feel close and connected to others?" Again, each of these needs also has a series of probes to help convey these constructs without the need for additional probes.

Analysis

A minimum of 400 participants will be enrolled to ensure sufficient statistical power for testing quantitative hypotheses. The calculation of power is informed by estimates of effect size obtained from the largest meta-analysis examining the relationship between need satisfaction/motivation according to self-determination theory and mental and physical health outcomes across various health contexts, which included 184 independent datasets.[57] For hypothesis 1, the association between need satisfaction and psychological/physical health, the meta-analyzed effect sizes suggest a power greater than .99. For hypothesis 2, the association between motivation and psychological/physical health, the expected power is .92. Lastly, for hypothesis 3, the indirect association between need satisfaction and psychological/physical health through self-determined motivation, the anticipated power is .80, a minimum acceptable level often recommended in social science research.[58] This power analysis ensures that the study is appropriately equipped to detect meaningful effects, reducing the risk of Type II errors.

To test hypotheses 1 and 2 with our primary outcome we will regress prolonged grief disorder onto need satisfaction, motivation for coping, and known risk factors/key covariates in a multivariate logistic regression model. The cutoff for statistical significance will be α=.05. Associations will be presented with 95% confidence intervals, unstandardized, and standardized effect sizes to indicate precision and magnitude of associations. To test hypothesis 3, we will specify a structural equation model that is identical to the regression specified above with the additional path of self-determined motivation regressed onto need satisfaction. The statistical significance cutoff will be a confidence interval that does not include zero. Indirect associations will be estimated through bootstrapping and presented with a 95% confidence interval, unstandardized, and standardized effect sizes.

Drawing from the overall sample, we will use the demographic information collected in the quantitative survey to identify bereaved AD/ADRD caregivers for qualitative semi-structured interviews. Participants will fall into one of three categories: a) spouses, b) adult-children, and c) extended family. We aim to recruit a total of 36-45 participants,12-15 from each of these categories. Our recruitment strategy will emphasize diversity within each of these relationship categories. We will consider factors including need satisfaction scores, race, ethnicity, gender, and age when selecting participants. This approach will enable us to gather insights from a wide range of perspectives. Additionally, the number of interviews that will be conducted aligns with an iterative inductive methodology,[59,60] allowing us to delve deeper into groups that provide distinct responses during the interview process.

We will explore experiences of need satisfaction through partially deductive systematic text condensation thematic analysis[61,62] in four steps: 1) total impression, 2) identifying and sorting by codes, 3) condensation from coding to meaning, 4) synthesizing information. We will hierarchically organize domains and experiences that provide need satisfaction to participants using self-determination theory’s perspective. Themes will be organized by the referenced need (autonomy, competence, relatedness), and who feels that the experience affects their needs (adult children, spouses, extended family). We are interested in the ways that need satisfying experiences align or diverge between subgroups of bereaved AD/ADRD caregivers. This strategy is considered partially *deductive* because the categories are driven by self-determination theory.[60] This strategy is partially *inductive* because it allows for new needs to emerge.[60] We will further explore whether need satisfaction sources differ within key subgroups by race/ethnicity and sex and will purposively sample additional members of those groups when answers differ.

Patient and Public Involvement

The research questions and materials for this study were informed by a diverse Community Advisory Board (CAB) of bereaved AD/ADRD caregivers and professionals known as the Supporting Dementia Caregivers After Death CAB. CAB members identify with different races, ethnicities, sexes, genders, ages, clinical specialties, types of dementia, time since bereavement, community organizations, and geographic locations. Specifically, in the K99 pilot phase, these individuals provided input on the type of questions that they felt were important to ask in addition to the proposed measures. This feedback shaped our survey and semi-structured interviews which were then reviewed again by the CAB before we started collecting data. As part of the pilot phase, 24 former dementia caregivers also received a survey or semi structured interview. This pilot phase was key in further modifying our measures for brevity, repetition and overall flow, shaping the measures used in the R00 phase.

Data

In compliance with the National Institutes of Health's data sharing rules, we will provide access to the final quantitative dataset and related documentation to other users via a data repository. Access to data will require a commitment to: use the data exclusively for research purposes; ensure no individual participant can be identified (although the data will be de-identified, there is still a small risk of deducing identities based on unique characteristics); and employ adequate data security measures.

Ethics and Dissemination

Arizona State University Human Subjects Institutional Review Board (STUDY00016256) gave expedited approval and supervises the study in alignment with requirements from the National Institutes of Health. Verbal consent is obtained from the bereaved AD/ADRD caregivers before proceeding with the surveys and interviews. During the pilot K99 phase, consent was achieved with a full consent form. To reduce participant burden, in line with direct participant feedback, changes were made to obtain consent verbally via telephone script. Signatures were also removed in consideration of participant risk in order to remove the link between personal information and survey responses. Modifications made during the R00 phase allow consent to be given to study staff based upon a shortened consent script as the project does not require full IRB review due to there being no greater than minimal risk to participants. In the script, highlights of the study are reviewed and the potential participant is iteratively asked for questions. This script is read to bereaved AD/ADRD caregivers at the beginning of both quantitative and qualitative components. The participant is then asked for approval for continued contact in future research projects. Participants are notified that approval is not required for participation in the current research. Additionally, participants are notified that resources for bereaved AD/ARD caregivers are available. Resources can be accessed via telephone during the interview and after by means of the Former Dementia Care Lab website.

We intend to disseminate the study's results via journal publications in gerontology journals and conferences. The results of this study are crucial to disseminate to advocacy organizations and healthcare professionals as a way to inform future interventions that aim to reduce the clinical and subclinical consequences of bereavement.

To all participants who approved further communication from the lab, a one-page concise explanation of the results will be sent via email along with a link to access the published findings. These one-page documents will be developed by the research team, shared with the CAB, and edited in accordance with their feedback prior to sharing with participants. We will then also host these documents on our lab website so that they are available to any interested individuals in the future. A unique one page document will be created for each publication in an academic journal.

Discussion

This study's aims use PATH-BAC, based on self-determination theory to understand the needs of bereaved AD/ADRD caregivers while accounting for the differences in the ways those needs are satisfied among key subgroups. The study also aims to qualitatively identify ways that bereaved AD/ADRD caregivers are already meeting their needs so that those strategies may be shared with other bereaved AD/ADRD caregivers who may be struggling. The wider goal of this research is to use the understanding of bereaved AD/ADRD caregivers' needs to create interventions to satisfy those needs, reducing the clinical and subclinical consequences of bereavement.

The focus on autonomy, competence, and relatedness provides flexibility in understanding and addressing diverse needs among bereaved AD/ADRD caregivers. This framework allows for a nuanced exploration of their experiences, which can be broadly applied. For example, in the context of the need for autonomy, adult child caregivers might be satisfied with newfound free time, while spousal caregivers may feel paralyzed by it. In this way, the same experience is subjectively very different, allowing researchers to better conceptualize bereaved AD/ADRD caregivers' phenomenological experience. Likewise, the needs for competence and relatedness are common to all caregivers[56] but may be satisfied in different ways for different kinds of bereaved AD/ADRD caregivers.

The proposed research is innovative in its focus on key subgroups, application of self-determination theory, and employment of a diverse CAB focused on bereaved AD/ADRD caregivers. Bereaved AD/ADRD caregivers are at elevated risk for clinically pathological and subclinically problematic consequences and their numbers are increasing quickly. The work will address the National Institute on Aging's goal to increase understanding of bereaved AD/ADRD caregivers' needs, informing future interventions that reduce the clinical and subclinical consequences of bereavement.

Figure 1. *Post-Caregiving Approach for Tending to Health in Bereaved AD/ADRD Caregivers (PATH-BAC) Model*

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Authors' Contributions

ZGB led the conception, design, and execution of the study, assuming the role of principal investigator for the project. JS and ANM, facilitated resource management, team mentorship, data curation, visualization, and supervision of the study. JS provided software support. JS, ANM, MGO, SGA, YH, OMN, IH, contributed to writing, review, and editing of the original manuscript. ANM and JS supplied protocol development and modification. All authors provided approval for the protocol to be published.

Competing Interests

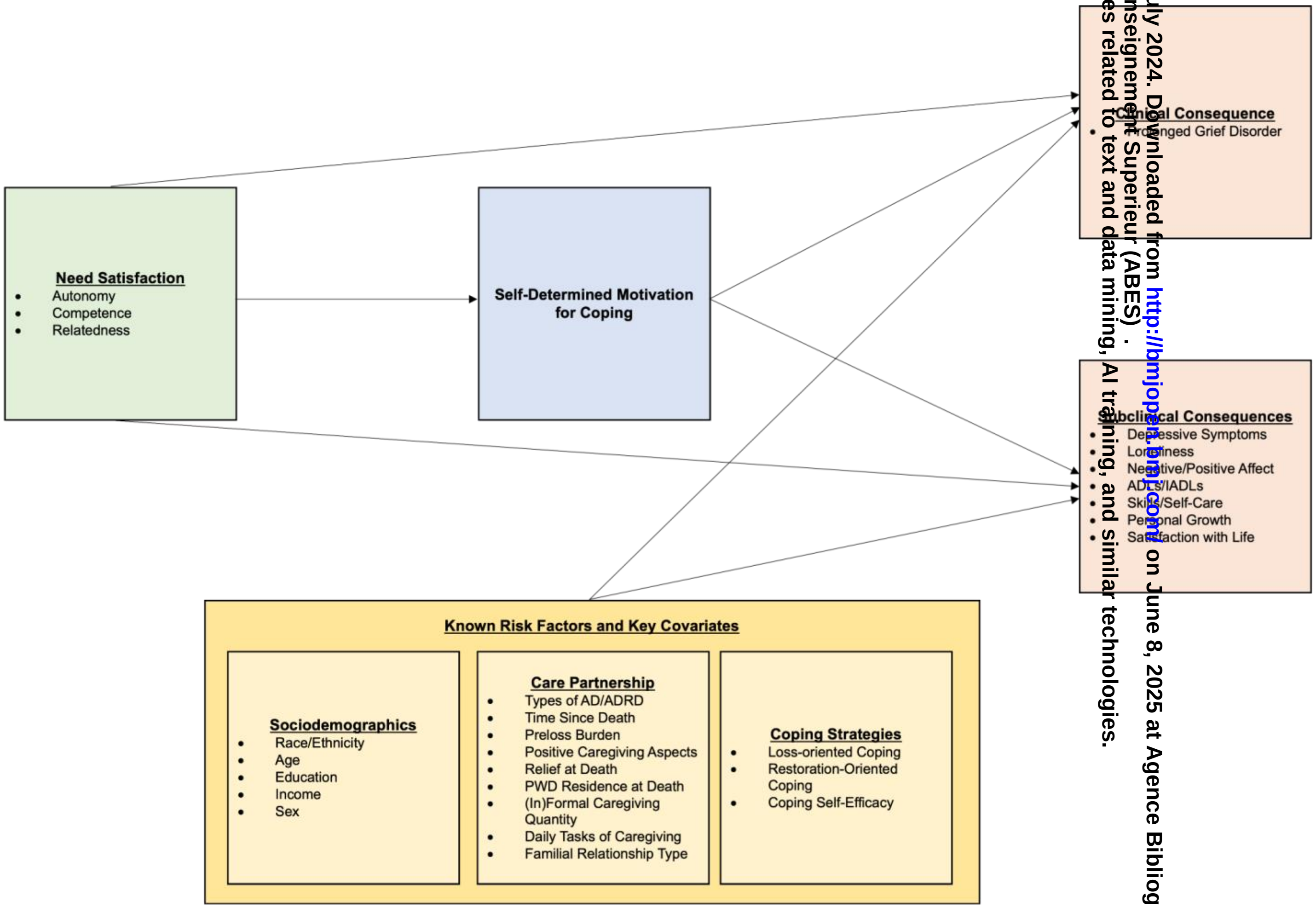
The authors have no competing interests.

Funding Statement

Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under Award Numbers R00AG073463. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Figure 1

Post-Caregiving Approach for Tending to Health in Bereaved AD/ADRD Caregivers (PATH-BAC) Model



<u>**Research Question**</u>**:** How do people who used to help with dementia care meet their needs?

<u>**Guide**</u>**:**
[Semi-structured interview guides are used as general templates for conversation about how former caregivers' needs are satisfied. Staff may add/modify/omit question prompts based on the responses.

Introduction: Thanks so much for being part of Learning from family and friends who helped with dementia care!! You taking the time to share your experiences with us is an incredible service. I say this because speaking with you and others like you is going to teach us a lot about how we can best support people who have helped care for folks who had dementia. Now, I would like to ask some questions to find out more about your experiences after the death of a person with dementia in your life. Rather than writing down the information you share, I would like to record this interview today for research purposes. [Set up recording if appropriate.]

-if they would like further information, this will:

a. allow me to be more present in the conversation rather than focusing on writing everything down.
b. allow the research team to carefully review your responses several times to ensure we capture everything you have taken the time to share with us.

1. **What is the name of the person with dementia who you used to help care for?**
    - **a.** *Interviewer please use this name in the place of "XXX" below.*

2. **Can you tell me a little more about your relationship with XXX [Use their name or the way the participant referred to them (e.g., "your mom")]?**

3. **As part of this project, we are trying to find ways to help people who have helped to care for a person with dementia after that person has died. Can you tell me a bit more about what life has been like for you since XXX died?**

Thank you for sharing that about your relationship with XXX. It is helpful for us to understand that context about your experiences.

My next set of questions will shift gear to ask more about life for you now.

4. **First, some people who helped with dementia care talk about the importance of having a sense of choice and freedom in the things that they do. What sorts of things give you a strong sense of choice or freedom?**

    PROBES:
    a. Perhaps something where your decisions reflect what you really want?
    b. What about a situation where what you're doing expresses who you really are?
    c. What about things you like doing just because they are really interesting or enjoyable to you?

5. **People who helped with dementia care also sometimes talk about the importance of feeling close and connected with others. What sorts of things help you feel close and connected to others?**

   PROBES

   a. What sorts of things make you feel included or like you belong with people you spend time with?
   b. What about a sense that people you care about also care about you?

6. **Another thing people who helped with dementia care talk about being important is feeling confident that they can do things well and achieve their goals. What makes you feel particularly confident and capable?**

   PROBES

   a. Sometimes we think of this as offering a challenge, but a challenge that is just the right level of difficulty. It's not too easy and not too hard.
   b. What about something where you set a goal that you did achieve or believe you will achieve?

Closing:
Thank you for sharing that, I can see how offering things like (*give 1-3 examples of things they do to meet needs*) to folks who helped with dementia care could be really beneficial.

7. **I have one final question today, what advice would you give a former dementia caregiver who's struggling?**

Thank you for taking the time to answer my questions today. Is there anything else you would like to share?

We couldn't do this research without people like you willing to take the time to talk with us. Do you know of any other caregivers who may be interested in this work?

a. If so, do you mind sharing their:
   i. Name
   ii. Best way to contact
   iii. Phone number
   iv. Email

Standards for Reporting Qualitative Research (SRQR)

O'Brien B.C., Harris, I.B., Beckman, T.J., Reed, D.A., & Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine, 89(9)*, 1245-1251.

No. Topic	Item	Page/Line no(s)
Title and abstract		
S1 Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	page 1, lines 1-2
S2 Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	Page 2-3, Lines18-43
Introduction		
S3 Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Pages 4 to 8, Lines 55 - 163
S4 Purpose or research question	Purpose of the study and specific objectives or questions	Page 9, Lines 165-180
Methods		
S5 Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	Page 16, Lines 318-329
S6 Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	Not Applicable for this mixed methods project
S7 Context	Setting/site and salient contextual factors; rationale[a]	Pages 10-11, Lines 187 - 221
S8 Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[a]	Pages 11 – 12, Lines 227-248
S9 Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security	Page 20, Lines 401-420

	issues	
S10 Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[a]	Page 16, Li 318-329
S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 16, L 318-32
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 16, Li 318-329
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	N/A
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale[a]	Pages 18- Lines 356-
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[a]	Page 19, L 381-39
Results/Findings		
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Not Applica
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Not Applica
Discussion		
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Not Applica
S19 Limitations	Trustworthiness and limitations of findings	Not Applica
Other		
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 26, L 538-53
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Pages 26-27, 540-544

Commented [JS1]: Authors should describe the participants, documents, or events included in the study (the units of study).The sampling item (Item 8) describes the target or ideal participants, documents, or events selected for the study. By contrast, Item 12 focuses on description of the actual participants, documents or events included in the study. Authors should describe how the actual participants, documents, or events differ from the targeted sample, why these differences may have occurred, and how this might affect the findings. Authors should describe characteristics of the participants, documents or events that are relevant to the study purpose and research question(s). For participants, this might include age, gender, profession, institution, year of training, or relationship to the researcher and/or other participants in the study.For documents, this might include the source, intended audience, date or type of document. For events, this might include the location, date(s), length, characteristics of attendees or participants in the event, or mood or emotional climate. If the degree of participation varied among individuals (e.g., multiple occasions; interviews and observations), the authors should describe different levels of participation. For example, if some participants were observed and interviewed and others only interviewed, or if some participants completed multiple interviews and others completed a single interview, these variations should be explained. Authors should also explain the reasons for these differences (i.e., the researchers' choice or the participants' preferences) and how these different levels of participation were taken into account in the analysis. Authors should also include the dates or timeframe for participation. This information about participants could appear in the Methods section as part of the description of the sample, or at the beginning of the Results section to provide context for the findings presented.

Commented [JS2]: Patient and Public Involvement?

Commented [JS3R2]: Authors should describe methods used to ensure trustworthiness and credibility throughout the data collection and analysis process. Such methods will depend on the paradigm, approach, and/or methods used. Correspondingly, the authors should explain their choice of techniques and why these are appropriate for the particular study.31,61,62 Commonly used techniques to enhance trustworthiness include: member checking; triangulation of data sources, methods, and/or researchers; creation of an explicit audit trail; and immersion in the site of data collection for an extended period of time (especially for research in which an observer's presence is

Commented [JS4]: None

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	**Recommendation**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract Title: page 1, lines 1-2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found Page 2-3 Lines18-43
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported Pages 4 to 8, Lines 55 - 163
Objectives	3	State specific objectives, including any prespecified hypotheses Page 9, Lines 165-180
Methods		
Study design	4	Present key elements of study design early in the paper Pages 9-10, Lines 182-186
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection Pages 10-11, Lines 187-221
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants Pages 11 – 12, Lines 227-248
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable Pages 14-16, Lines 279 - 317
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group Pages 15-16, Lines 304-329
Bias	9	Describe any efforts to address potential sources of bias Pages 14-15, Lines 274-303
Study size	10	Explain how the study size was arrived at Pages, 16-17, Lines 330-355
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why Pages, 16-17, Lines 330-355
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding Pages, 16-17, Lines 330-355
		(*b*) Describe any methods used to examine subgroups and interactions N/A
		(*c*) Explain how missing data were addressed N/A
		(*d*) If applicable, describe analytical methods taking account of sampling strategy N/A
		(*e*) Describe any sensitivity analyses N/A

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed N/A
		(b) Give reasons for non-participation at each stage N/A
		(c) Consider use of a flow diagram N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders N/A
		(b) Indicate number of participants with missing data for each variable of interest N/A
Outcome data	15*	Report numbers of outcome events or summary measures N/A
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included N/A
		(*b*) Report category boundaries when continuous variables were categorized N/A
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses N/A
Discussion		
Key results	18	Summarise key results with reference to study objectives N/A
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias Page 3, Lines 50-53
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence N/A
Generalisability	21	Discuss the generalisability (external validity) of the study results N/A
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based Pages 26-27, Lines 540-544

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.