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WASHINGTON UNIVERSITY IN ST. LOUIS

Department of Psychology

Dissertation Examination Committee:

Brian D. Carpenter, Chair

Wendy Love Anderson

Jan Duchek

Denise Head

Lori Markson

Nancy Morrow-Howell

Effect of Reading and Discussing a Storybook about Alzheimer's Disease on Children and
Parents

by

Erin Yukie Sakai

A dissertation presented to the
Graduate School of Arts and Sciences
of Washington University in
partial fulfillment of the
requirements for the degree
of Doctor of Philosophy

August 2014

St. Louis, Missouri

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Acknowledgements

There are many without whom I could not have dreamed of accomplishing this project. First, I wish to thank my advisor and mentor, Brian Carpenter, for his significant dedication to my training. His practical guidance and willingness to challenge me, coupled with his encouragement and enthusiasm not only during the course of this project, but throughout my graduate training, has been invaluable. I am also grateful to the members of my dissertation committee, Wendy Anderson, Jan Duchek, Denise Head, Lori Markson, and Nancy Morrow-Howell, for their thoughtful discussion and feedback throughout the dissertation process.

Recognizing the commitment of research participation, I am greatly appreciative of the many young children and parents who participated in this study. It is through their enthusiasm that this project, and future research in this area, could take place. I also appreciate those who facilitated recruitment, including Dr. Lori Markson, the Ladue School District, and the University City School District.

In addition, I would like to thank the past and current members of the Clinical Geropsychology Lab for their perspectives on clinical, scholarly, and professional issues. These discussions have shaped my conceptualization and approach to aging and older adulthood.

Finally, I am grateful for the support that my family and friends have provided throughout the years. Their encouragement and belief in me has inspired me during this journey.

Dedication

To my grandparents. It is through my relationships with you that I came to recognize my passion for working with older adults and their families. The values and support that you have provided our family are inestimable.

ABSTRACT OF THE DISSERTATION

by

Erin Yukie Sakai

Doctor of Philosophy in Psychology

Washington University in St. Louis, 2014

Professor Brian D. Carpenter, Chair

Currently, there are 5.2 million Americans over the age of 65 with Alzheimer's disease (AD; Alzheimer's Association, 2013). Given the growing proportion of the population that is over age 65, the number of people who will develop Alzheimer's disease is expected to increase significantly over the next 20 years. One consequence of that trend is that more young children (i.e., ages 4-12) are likely to encounter AD through a grandparent or great-grandparent with the disease. While it is unknown exactly how many young children have grandparents or great-grandparents with the disease, 30 percent of dementia caregivers also have children under 18 years old (National Alliance for Caregiving & AARP, 2009), suggesting that dementia does, in fact, have an impact on many children.

Alzheimer's disease can affect young children in many ways: children may experience confusion about their relative's condition or their changed relationship with their relative, they may feel isolated or neglected due to decreased attention from parents who are in AD caregiving roles, and they may be asked to take on additional household chores or caregiving responsibilities themselves. Yet, there are few opportunities for young children to receive information about AD, despite the fact that this information may influence their attitudes and responses to AD and people with AD. Among the different ways children can learn about AD,

storybooks are one way of presenting children with information about AD, with potential benefits for children *and* for parents.

The current study utilized a within-subjects, repeated-measures design with two interventions, 1) reading a storybook about AD to young children, and 2) having a subsequent discussion about the book with their children. Outcome measures for children and parents included AD knowledge, attitudes about AD, willingness to interact with people with AD, as well as emotional responses to the AD storybook (i.e., positive and negative affect). Parent self-perceived confidence in discussing AD with their children was also assessed. In addition, child and parent satisfaction with the storybook and discussion was evaluated. Fifty-five parent-child dyads participated in this study. There was a significant overall effect of the interventions on both the child and parent dependent variables, particularly after reading the storybook, with AD knowledge increasing, attitudes improving, and willingness to interact with individuals with AD increasing. Meanwhile, the interventions did not appear to have a negative impact on child or parent emotions. The findings from this study suggest that storybooks can, in fact, be useful tools for providing information and influencing attitudes and behaviors in the context of AD for both young children and their parents. Results from this study may provide an initial step toward identifying appropriate interventions to increase AD health literacy in both young children and their parents.

Introduction

Children's Experience and Understanding of Alzheimer's Disease

Alzheimer's disease (AD) has an impact on the entire family well beyond just the person with the disease. However, while there is an abundant scientific and clinical literature focused on patient-caregiver relationships in AD, the impact of the disease on young children has been virtually ignored (Hamill, 2012; Howard & Singleton, 2001). Yet children are aware of the impact of AD on the people around them (Mace & Rabins, 1999), and may experience secondary effects of AD in a variety of ways.

Individuals with AD often exhibit unusual behaviors because of their disease, such as repetition of stories, paranoid or suspicious beliefs, or poor judgment. These behaviors can be unsettling to young children, and children may be uncertain how to respond to them. Further, the language difficulties of people with AD may complicate children's ability to communicate with them, leaving children with a limited understanding of individuals' direct experiences of AD (Magnuson, 1999). As a consequence, children may be confused when they encounter people with AD and experience changes in their relationship with individuals with AD. In one study, for instance, 37% of adolescents (ages 14-21) indicated that their relationship with their grandparent had become worse after the AD diagnosis (Celdran, 2011). These participants reported less contact, emotional closeness, and satisfaction in their relationships with their grandparents following the AD diagnosis. In another study, children (ages 8-18) with grandparents with AD reported less companionship, instrumental help, intimacy, affection, admiration, and satisfaction from their relationship with their grandparent than children with grandparents who did not have AD (Creasey, Myers, Epperson, & Taylor, 1989). In this study, burden on the child's mother accounted for a substantial amount of the variance in predicting

child-grandparent relationships, confirming the complicated intergenerational dynamics involved in caring for someone with AD. In addition, children whose mothers were more burdened by AD caregiving perceived more negative interactions in their own relationships with their grandparents and decreased satisfaction in that relationship (Creasey & Jarvis, 1989). The degree to which children are affected by AD appears to depend on children's type of relationship with the person with AD (e.g., grandparent versus family friend, etc.), children's emotional closeness to the individual, and their geographic proximity to the person (Alzheimer's Association, 2011; Hamill, 2012).

Meanwhile, having grandparents with AD can also influence children's relationships with other family members. Consistent with a family systems perspective, the stress experienced by one member of the family can have an impact on everyone. For example, greater maternal AD caregiver burden was associated with children (ages 8-18) feeling less support (e.g., affection, intimacy, and companionship) and satisfaction in their relationships with their *fathers* (Creasey & Jarvis, 1989). The authors suggest that this phenomenon could be due to children's recognition of fathers who are unsupportive of their spouses.

In addition to evolving relationships with family members, children may experience decreased social engagement when a relative has AD. Parents who are caregivers for individuals with AD may have less time or energy to spend with their young children (Mace & Rabins, 1999). Further, in order to provide support to their parents, young children may have additional household or caregiving responsibilities, which could cause more limited social engagement with their friends (Goodnow & Lawrence, 2001). Indeed, children with parents more burdened by AD caregiving provide more assistance to their grandparents with AD (Hamill, 2012).

Finally, children may respond to people with AD with a range of emotions. For example, some children may feel guilt, believing that they were responsible for their grandparent's AD or contributed to their grandparent's deterioration (Mace & Rabins, 1999). Others may experience embarrassment associated with their grandparents' behavior. For example, in one Taiwanese study, children reported that they would feel embarrassed about having friends visit their home if a grandparent with AD lived with them (Fuh, Wang, & Juang, 2005). Still other children may feel anger or resentment associated with the decreased attention from parents or the restrictions on their social lives. Many younger children also describe fear, both about the potential loss of their grandparent and concern that the disease might be contagious (Fruhauf, & Orel, 2008). In addition, children may mourn the loss of their relationship with their grandparent. Despite these negative emotions, children also report positive emotions, such as feeling satisfied with helping the family with caregiving (Celdran, 2011). Ultimately, children may develop a complex emotional response that involves multiple, competing feelings (Mace & Rabins, 1999; Orel & Dupuy, 2002).

While children may notice changes in the individual with AD or alterations in their own lives, they may have few direct conversations about these changes with their parents. Some parents shield young children from health information and experiences (Wolf, et al., 2009). Other parents may not discuss AD with young children because of limited time or low confidence in their own AD knowledge. Consequently, children may possess a limited or inaccurate understanding of AD, which can deepen their discomfort with people who have AD. Thus, child education about AD may reduce confusion about the disease and enable children to feel more comfortable around people who have it.

Dementia Health Literacy among Children

The U.S. Department of Health and Human Services (2000) defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. 20). Health literacy depends not only on cognitive abilities, such as basic reading skills, but also on an individual’s ability to analyze and apply their knowledge (Betz, Ruccione, Meeske, Smith, & Chang, 2008; Wolf, et al., 2009). Child health literacy is also dependent upon both parent and child understanding of health (Abrams, Klass, & Dreyer, 2009). Over time, children’s health literacy is influenced both by parental modeling of behaviors and children’s own understanding of health concepts through the acquisition of information. According to Piagetian theory, even by age 2, children are able to associate illness with a vague sense of feeling “bad” (Borzekowski, 2009).

Several programs have attempted to familiarize children with AD through exposure to people with the disease. The goal of these interventions is to increase meaningful contact between children and individuals with AD, enhance children’s appreciation of older adults’ experiences, and provide older adults with opportunities for enjoyable social interactions. In one study, parents of children, 12- to 54-months old, in an intergenerational daycare program reported that their children enjoyed interacting with the older adults with dementia and benefitted from exposure to diverse people and individualized attention from the older adults with dementia (Jarrott & Bruno, 2007). Another study by Femia, Zarit, Blair, Jarrott, and Bruno (2008) examined the effect of attending a preschool that had an intergenerational program including individuals with cognitive disabilities. Children who had been in the intergenerational program had higher levels of acceptance, more empathy, and slightly more positive attitudes toward

individuals with AD than children who had attended a single-generation program. Thus, it is feasible that early exposure to people with AD may positively influence children's attitudinal, behavioral, and emotional responses to people with AD.

Meanwhile, adult AD knowledge can have implications for children's views. Given that children's responses to health are heavily influenced by parents' health literacy, parental misconceptions about aging and AD can affect young children. It is possible that parents with inaccurate information may respond inappropriately to cognitive or behavioral changes in people with AD, which may subsequently perpetuate misinformation in children. Indeed, previous studies have found that lay persons' knowledge of AD is limited (Carpenter et al., 2011; Werner, 2001, 2003), and inadequate knowledge about AD may trickle down to other family members (Mace & Rabins, 1999). However, interventions can, in fact, improve knowledge in adults. For example, fotonovelas, stories told in a pictorial format popular in the Latino/Hispanic communities, increase AD knowledge among Spanish-speaking older adults (Valle, Yamada, & Matiella, 2006).

While there have been some studies examining AD knowledge among adult lay persons, to my knowledge none have examined children's knowledge of AD. However, there have been recent attempts to increase children's understanding of AD. For example, organizations such as the Alzheimer's Association have web pages dedicated to educating young children and teenagers about the disease as well as information sheets for parents with recommended activities and ways to help children cope (Alzheimer's Association, 2011, 2013). Likewise, *The Alzheimer's Project*, a recent documentary about AD, includes a portrayal of the experiences of young children with grandparents who have AD (Home Box Office, 2012). While organizations recommend that parents have honest conversations with their children about the changes that are

occurring throughout the family, they provide few specific suggestions about how to have those conversations (Alzheimer's Association 2011; Alzheimer's Disease Education and Referral Center, 2009). Thus, it is important to identify and evaluate more specific techniques for providing children with information about AD. Given the growing recognition of the importance of AD health literacy, it is appropriate to identify a framework for promoting appropriate knowledge and behaviors in young children. Bandura's social cognitive theory (Bandura, 2004) may be one useful framework.

Social Cognitive Theory and Health Promotion

Bandura's social cognitive theory (SCT; Bandura 2004) is frequently used to guide health promotion interventions because it describes how people change their behaviors by learning from their experiences, make decisions based on the expectations and value that they put on the outcome of their behavior, and have the ability to regulate their behavior (Simons-Morton, McLeroy, & Wendel, 2012). More generally, SCT provides a basic framework for understanding how educational materials, such as a storybook, can promote improved health attitudes and behaviors. In the context of health promotion, knowledge is a necessary precondition to behavior change and must be accurate and relevant (Bandura, 2004; Sharma & Romas, 2012). Further, the theory suggests that learning is not only experiential, but also acquired vicariously through observation. People can then utilize information based on the feedback they receive from their environment and their own behaviors and cognitions (Bandura, 1977). In the case of children learning about AD, SCT suggests that children must first acquire information about AD both through observation of others (e.g., parents) and experience; subsequently, feedback from parents and other sources can reinforce children's thoughts (e.g., attitudes about AD and people who have AD) and behaviors (e.g., engaging with people with AD).

In addition to a more general explanation of health attitude and behavior changes, SCT suggests the specific components that influence learning. According to Bandura (1977), the observer, the individual performing the behavior (i.e., the model), and the modeled behavior itself all contribute to the effectiveness of the modeling. Characteristics of the observer, such as personality, motivational factors, previous experiences, expectations of outcomes, and values of those expectations, can all affect the likelihood that behaviors change once they have been observed (Bandura, 1977; Simons-Morton, McLeroy, & Wendel, 2012). Likewise, observers are more likely to attend to models that are similar to them in characteristics and status (Bussey & Perry, 1976). Finally, the complexity and functional value of the behaviors themselves, the uncertainty about what behaviors are appropriate in a given situation, and the consequences of the modeled behavior (i.e., extent to which behaviors are highly rewarded or punished) strongly influence their effectiveness (Bandura, 1986).

According to SCT, storybooks, then, may be a useful means for providing information about AD by modeling thoughts, feelings, and behaviors/coping mechanisms that children and parents may experience when interacting with someone with AD. More specifically, the characters in the storybook, who serve as models, and the behaviors that are modeled in the books, influence the likelihood that children and parents will demonstrate attitude or behavior changes.

Benefits of Storybooks

As suggested by SCT, storybooks could be one means for promoting behavior change in children, as children have the opportunity to learn new information and behaviors. First, storybooks are a source of information for young children and can provide basic details about health issues such as Alzheimer's disease. Even by age 4, children are able to learn new

information from picture books and apply that information to real-world circumstances (Ganea, Ma, & DeLoache, 2011; Ganea, Pickard, & DeLoache, 2008). Since SCT suggests that knowledge is a precursor to behavior change, the storybook's role in providing information about AD may be one fundamental benefit.

Further, consistent with SCT, storybook characters can serve as models to young readers and their parents. Children can observe problems experienced by characters and the solutions that are developed and can then apply those strategies to their own problems (Berns, 2004). In addition, storybook characters with experiences similar to those of young readers can help children recognize that they are not alone in their experience (Pardeck & Pardeck, 1993). A recent study from our laboratory that examined characteristics of AD storybooks found that they contain plot and character features that model adaptive behaviors and coping strategies (Sakai, Carpenter, & Rieger, 2013).

Another benefit of storybooks is that they facilitate understanding of sensitive issues. As a form of bibliotherapy, storybooks can present difficult situations in a nonthreatening manner (Alton & Lanning, 1979; Cohen, 1987). Storybooks can illustrate abstract concepts in concrete ways and help young children explore difficult emotional concepts (Shepherd & Koberstein, 1989). Children can become emotionally involved in storybooks and can subsequently process their emotions within the safe context of the book (Pardeck & Pardeck, 1993). Consistent with SCT, models in storybooks can also provide young readers with a sense of self-efficacy for feared events or experiences by illustrating coping strategies (Bandura, 2001).

There can be added benefits when book reading stimulates further discussion. Prior research has shown that parental book discussions, and more specifically, utilization of open-ended questions, expanding and recasting children's responses, and providing corrective

feedback, can contribute to children's cognitive development (Blewitt, Rump, Shealy, & Cook, 2009; Greenhough, 1998; Hudson & Test, 2011; Whitehurst, et al., 1988). In addition, it has more recently been recognized that storybooks can influence children's social cognition, by exposing children to social situations and illustrating characters' emotions, thoughts, and beliefs (Aram, Fine, & Ziv, 2013). Studies have suggested that discussing book characters' thoughts and emotions can increase children's understandings of other people's thoughts (e.g., Symons, et al., 2005) and emotions (LaBounty, Wellman, Olson, Lagattuta, & Liu, 2008; Ornaghi, Brockmeier, & Gavazzi, 2011; Whitehurst, et al, 1994). Thus, discussion of concepts depicted in storybooks can potentially supplement simply reading the storybook for children.

In addition to benefits for children, reading storybooks may benefit parents. Consistent with SCT, parental characters in the storybooks may model behaviors for parents (Bandura, 1977) by depicting socially appropriate ways of interacting with people with dementia and with their children. In addition, parents' self-competence in discussing health topics with children may improve when they are provided information about AD in storybooks and teach children this information. While I do not know of studies examining the effects on parents of reading books about health topics to children, teachers using children's books as part of a health education curriculum reported greater confidence in their ability to teach health information after reading to their students (Deal, Jenkins, Deal, & Byra, 2010). It is possible that parents could gain similar confidence when reading and discussing AD with their children.

Storybooks and Health Education

Existing bibliotherapy resources for children address many domains including sibling rivalry, moving, divorce, and accepting individual differences (Cohen, 1987; Jalongo, 1983). In addition, a number of research articles have highlighted the portrayal of health issues in

children's picture books. Topics have included physical injury (Turner, 2006), death (Malcom, 2010; Poling & Hupp, 2008; Seibert & Drolet, 1993), anesthesia treatment (Rawlinson & Short, 2007), and developmental disability (Dyches & Prater, 2005; Dyches, Prater, & Cramer, 2001). However, most studies examining the effects of storybooks about health are descriptive in nature, and other health education reading interventions with children are rare. These studies have generally found that storybooks can be helpful in increasing knowledge (Thornton, 1996), changing attitudes (Byrne, 2002), and influencing health behaviors (Robinson, Calmes, & Bazargan, 2008). Overall, these few studies provide equivocal evidence about whether storybooks can be helpful for discussing health problems with children.

While many organizations such as the Alzheimer's Association and the National Institute of Aging publicize book lists with recommended reading about dementia for children, thus far, there has been no empirical research to support reading storybooks about AD to children. Previous studies have examined the themes or characteristics of children's storybooks about AD (e.g., Manthorpe, 2005; Sakai, Carpenter, & Rieger, 2012), but this dissertation is the first study to examine whether reading books about Alzheimer's disease produces actual change in knowledge, attitudes, behaviors, and emotions in young children and their parents.

Study Aims

The purpose of this dissertation is to examine the impact of reading and subsequently discussing a storybook about Alzheimer's disease with young children. The study utilizes a within-subjects, repeated-measures design that consists of two interventions, 1) reading and 2) discussing a storybook. Measurement of outcomes occurs at three time points (see Figure 1). Based on the tenets of social cognitive theory, I hypothesized that reading the storybook would improve child knowledge, as well as child and parent attitudes, and willingness to interact with

people with AD. Given the literature on shared reading, which suggests that interaction between the child and the person reading the storybook improves child literacy, I hypothesized that discussing the storybook would increase child knowledge, attitudes, and willingness over and beyond reading the book. Further, given literature suggesting that learning increases after teaching, discussing the storybook is expected to increase parent attitudes, willingness to interact with people with AD. In addition, reading the storybook would increase parent self-perceived competence in discussing AD with their children, and discussing the storybook would increase their self-perceived competence further. Reading the storybook would decrease negative affect and increase positive affect; it is unclear from the literature how discussing the storybook would influence affect. Finally, I predicted that children and parents would report satisfaction with the storybook and AD discussion.

Methods

Participants

The 55 dyads in this study included a 7- or 8-year old child and one parent. Participants were recruited through the Cognition and Development Database at Washington University and elementary schools in the greater St. Louis area. In order to be included in this study, both children and parents needed to be fluent in English, and parents were required to be literate at the 10th grade level. In addition, parent-child dyads were excluded if children had developmental disabilities.

Because there have been no previous studies that have used a similar intervention and design, sample size was determined based on effect sizes reported in studies involving psychoeducational materials with children, such as computer education, audiotapes, videotapes, slide-tape, and therapeutic play (Bonner & Everett, 1982; Coleman & Kaplan, 1990; Gaust,

Olson, & Rodriguez, 1991; Li, 2007; Rowe & Jacobs, 2002). In these studies, reported effect sizes are moderate to large ($d = 0.50-1.80$), and so for the current study, the sample size was determined based on a conservative, medium effect. The effect size for repeated measures MANOVA is f , and according to Cohen (1969), a medium effect is reflected by $f = 0.25$. G*power (Faul, Erdfelder, Buchner, & Lang, 2009) was used to determine the sample size necessary for a one-way, within-subjects, repeated measures MANOVA design, using a medium effect ($f = 0.25$), power = 0.80, alpha = 0.05, with three groups and five variables. This resulted in a sample size of 55 dyads.

Design

This study utilizes a within-subjects, repeated-measures design that consists of two interventions and measurements at three time points (see Figure 1). Demographic and baseline data were collected from children and parents prior to reading the storybook (T1). The examiner presented the questionnaires orally to the children at all assessment points. Meanwhile, parents completed their questionnaire in a separate room. Then parents read the AD storybook to their children. Book reading generally took 12-15 minutes. Outcome data were collected following book reading (T2), with children and parents again completing questionnaires separately. After T2 assessments, parents rejoined the children and engaged in a 12-minute discussion about the content of the book, application of the book to children's lives, and children's reactions to the book. Parents received a discussion guide with potential topics and questions (see Appendix I); they were instructed to ask at least one of the questions in each domain. Study administrators were instructed to listen to the discussion between child and parent and to notify parents if they did not ask at least one question in each domain. However, data indicating whether parents followed instructions were not recorded. Outcome measures were repeated after the discussion

(T3) for both parents and children, with the exception that rather than reporting on their satisfaction with the book, parents and children rated their satisfaction with the discussion. Sessions generally took 1–1.5 hours in total. The author and trained undergraduate research assistants were responsible for data collection.

Materials

The book that parents read to their children in this study was *Allie Learns about Alzheimer's Disease* (Gosselin, 2001). Selection was based on a paper examining the depiction of AD symptoms in children's storybooks (Sakai, Carpenter, & Rieger, 2012) and a review of 33 children's fiction, storybooks, published between 1988 and 2009 that address Alzheimer's disease (Sakai, Carpenter, & Rieger 2013). The latter review examined the features of the characters in these books, their responses and behaviors, and the extent to which they engage in coping behaviors. This book tells the story of a young girl who witnesses her grandmother's decline associated with AD. It was chosen because it depicts many aspects of the Alzheimer's experience, such as a variety of cognitive and emotional symptoms associated with AD and the diagnostic process and treatment. In addition, the book illustrates the child's emotions as well as child and parent behaviors in response to the grandmother's symptoms. According to material on the jacket, the book is written for children ages 5 years and older.

A discussion guide was created for parents to use during a conversation following the book reading (see Appendix I). Questions in the discussion guide were developed from suggested topics provided in other AD storybooks (Frantti, 2002; Pollack & Belviso, 2009; Schnurbush, 2007), as well as from suggestions from the Alzheimer's Association parent and teacher resource list (Alzheimer's Association, 2011).

Measures

Children.

Demographics.

Children's demographic characteristics and experience with books were collected from their parent (see Parent section below). Children answered one question about how much they enjoy reading (1 = *not at all*, 2 = *a little bit*, 3 = *quite a bit*, 4 = *a lot*) and whether they had heard of Alzheimer's disease before (1 = no, 2 = yes).

Reading comprehension.

Reading comprehension was assessed using the Understanding Spoken Paragraphs subtest of the Clinical Evaluation of Language Fundamentals, Fourth edition (CELF; Semel & Wiig, 2003). Administration of the CELF-4 involves having an examiner read three paragraphs to the child. The child answers five questions per paragraph that evaluate understanding of the paragraph's main idea and ability to go beyond the information provided. Scores can range from 0-15 such that higher scores reflect greater comprehension. According to the manual, the Understanding Spoken Paragraphs subtest was moderately correlated with the other CELF-4 subtests, with intercorrelations ranging from .39-.51 (Semel & Wiig, 2003). Internal consistency for the Understanding Spoken Paragraphs subtest in the current sample was 0.64 for 7-year-olds and 0.74 for 8-year-olds. The split-half reliability for 7- and 8-year-olds was .68 and .79, respectively. The developers of the test suggest that the low reliability on this subtest is likely due to the short subtest length.

Knowledge about Alzheimer's disease.

Because there are no AD knowledge scales that have been developed for use with young children, knowledge questions were written based on the information presented in the storybook used in this study. Twenty true-false items were written to assess the information provided in the

book (see Appendix II). Items addressed AD symptoms, assessment and diagnosis, impact on life, and treatment. Correct answers were summed. Scores can range from 0 to 20; high scores indicate greater AD knowledge.

Attitudes toward people with Alzheimer's disease.

Because there are no AD attitude scales that have been developed for use with young children, a new scale was created for this study, adapted from the Dementia Attitudes Scale (DAS; O'Connor & McFadden, 2010) and an instrument measuring attitudes about AD developed by Lundquist & Ready (2008). O'Connor and McFadden (2010) identified two factors on their scale, "social comfort" ($\alpha = 0.75$) and "dementia knowledge" ($\alpha = 0.82$). The "social comfort" factor reflects individuals' feelings of comfort with people who have AD. The "dementia knowledge" factor reflects people's knowledge and beliefs about AD. While the factor was labeled "dementia knowledge," the items do not reflect factual aspects of AD. Some examples include, "It is possible to enjoy spending time with people with AD," "People with AD can enjoy life," and "People with AD can feel when others are kind to them." Lundquist and Ready's scale also contained two factors, "personal sacrifice" ($\alpha = 0.72$) and "sympathy" ($\alpha = 0.52$). The "personal sacrifice" factor includes items that capture willingness to make personal sacrifices for people with AD, and the "sympathy" factor reflects feelings toward or about individuals with AD. Because both instruments were developed using undergraduate populations, for the current study a subset of items was chosen for use with children. Ten items were retained that had 1) high factor loadings (0.41- 0.74) in the validation study, and 2) content that was likely to be comprehensible to young children. The 10 items include statements that reflect all four factors identified in the studies mentioned above, and the language of the questions was simplified for use with a younger sample based on the responses of the pilot

families (see Appendix III). Participants were asked to indicate how much they agree with statements about individuals with AD. The modified response scale utilizes a 4-point Likert-type scale that is easier for children to use (1 = *strongly disagree*, 2 = *disagree*, 3 = *agree*, 4 = *strongly agree*). Responses are summed. Scores on this scale can range from 10 to 40, with higher scores indicating more favorable attitudes toward people with AD.

Emotional response following storybook reading and discussion.

The 10-item Positive and Negative Affect Scale for Children (10-item PANAS-C; Ebesutani, et al., 2012) was used to assess children's emotional responses during the course of the study. The 5 positive items and 5 negative items are rated on a 5-point Likert-type scale (1 = *very slightly or not at all*, 2 = *a little*, 3 = *moderately*, 4 = *quite a bit*, 5 = *extremely*). Responses are summed, and total scores can range from 10 to 50. In previous research the positive and negative affect scales were found to have good internal consistency ($\alpha = .86$ and $\alpha = .82$, respectively) with children between 6 and 18 years old (Ebesutani, et al., 2012). In the current sample, internal consistency for the child willingness scale was acceptable ($\alpha = .75-.84$). As with parents, child reliability on the 10-item PANAS-C was good, ranging from $\alpha = .84-.91$ and $\alpha = .74-.83$ for positive and negative affect, respectively. In addition, the positive and negative affect scales on the 10-item PANAS-C were demonstrated to have divergent validity as well as the ability to differentiate between youths with clinical disorders and those without them (Ebesutani, et al., 2012).

Willingness to engage in AD approach behaviors.

A scale measuring children's willingness to engage in a variety of behaviors with an individual with AD was developed based on 1) suggested activities in several other children's books depicting AD (Pollack & Belviso, 2009; Schnurbush, 2007) and 2) findings of an earlier

study examining the portrayal of AD in children's storybooks (Sakai, Carpenter, & Rieger, 2013). The scale consists of 9 items that capture ways to interact with people who have AD (e.g., learn more about Alzheimer's disease, spend more time with the person who has Alzheimer's disease; see Appendix IV). Children rated their willingness to engage in each behavior on a 4-point Likert-type scale (1=*not at all*, 2 = *a little bit*, 3 = *quite a bit*, 4= *a lot*). Responses are summed, and scores can range from 9 - 36, with higher scores reflecting greater willingness to do the behaviors.

Satisfaction with book and discussion.

Three questions were developed based on items in other studies evaluating intervention satisfaction (e.g., Glang, et al., 2005). Questions included, "How much did you like this book?", "How much did you understand this book?", and "How much more do you know about AD after reading the book?" Questions were answered on a 4-point Likert-type scale (1 = *not at all*, 2 = *a little bit*, 3 = *quite a bit*, 4 = *a lot*). In addition, children rated their likelihood of recommending the book to others and reading the book again. Both of these items were rated on a 4-point Likert-type scale (1 = *not at all*, 2 = *somewhat likely*, 3 = *quite likely*, 4 = *very much likely*). Following the discussion, children reported their satisfaction with the discussion with one item rated on a 4-point Likert scale (1 = *not at all*, 2 = *a little bit*, 3 = *quite a bit*, 4 = *a lot*): "Did you like talking with your parent about the book?"

Parents.

Demographics.

Parents completed demographic questions including age, gender, race/ethnicity, and highest level of education completed. They also reported demographic information for their children including age, gender, race/ethnicity, and education (current grade in school). For

descriptive purposes, parents indicated the approximate number of children's books in their home and the average amount of parent reading time with the child, and child-only reading time, in a week (in hours).

Experience with Alzheimer's disease.

Parents reported the number of people with AD their children knew. They also indicated their children's frequency of contact (1 = *less than 6 times per year*, 2 = *monthly*, 3 = *weekly*, 4 = *daily*; 0 = *not applicable*) and emotional closeness to these individuals with AD as a group (1 = *not at all close*, 2 = *a little close*, 3 = *mostly close*, 4 = *very close*; 0 = *not applicable*). In addition, parents reported their own experience with AD, including their relationship to individuals with AD, current or former cohabitation with people with AD, and work or volunteer experience, using dichotomous yes/no responses. They also indicated the frequency of contact (1 = *less than six times per year*, 2 = *monthly*, 3 = *weekly*, 4 = *daily*; 0 = *not applicable*) and emotional closeness (1 = *not at all close*, 2 = *a little close*, 3 = *mostly close*, 4 = *very close*; 0 = *not applicable*) to these individuals.

Knowledge about Alzheimer's disease.

A baseline measure of parent AD knowledge was assessed using the Alzheimer's Disease Knowledge Scale (ADKS; Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009). This 30-item, true/false scale examines knowledge about AD risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment. Internal consistency ($\alpha = .71$) and split-half reliability ($\alpha = .55$) were acceptable in the development sample. In this study, the ADKS was used as a measure of pre-existing AD knowledge rather than an outcome measure of knowledge because the intervention was not expected to influence ADKS scores given the relative simplicity of the book compared to the more nuanced topics on the ADKS. In this

sample, parent KR-20 reliability of the ADKS was $\alpha = .66$, which is slightly lower than the reliability found in the development study ($\alpha = .71$).

Parents were also administered the child Alzheimer's disease knowledge scale (described above) in order to assess the impact of the interventions on parent AD knowledge. Since parent scores on the child Alzheimer's disease knowledge scale were expected to be high at baseline, parents only completed this assessment at baseline and after the last intervention in order to reduce participant burden. Reliability of parent scores on the child AD knowledge scale ranged from $-.471$ to $-.083$. Since all parents correctly responded to items, there was no variance on the responses of the participants on 7 to 11 items. Thus, these items were dropped from the reliability analysis. Fewer items on a scale results in lower internal consistency. In this case, low internal consistency was likely due to the lack of variance among participants, which reduced the number of items included in the analysis. In this sample, the child AD knowledge scale has good convergent validity, as the parent scores on this assessment at baseline correlated positively with parent ADKS scores ($r = .436$; $p = .001$).

Attitudes toward people with Alzheimer's disease.

Parents' attitudes toward people with AD were measured using the Dementia Attitudes Scale (DAS; O'Connor & McFadden, 2010), which assesses the cognitive, affective, and behavioral components of attitudes toward patients with Alzheimer's disease. It is a 20-item scale that utilizes a 7-point Likert-type format (1= *strongly disagree*, 7= *strongly agree*). Responses are summed, and scores can range from 20-140, with higher scores indicating more positive attitudes. The scale has a two-factor structure which the authors labeled "social comfort" ($\alpha = .82$) and "dementia knowledge" ($\alpha = .75$). O'Connor and McFadden (2010) found that the scale has adequate construct validity when compared with other scales assessing

attitudes toward older adults and disabled individuals. The internal consistency of the Dementia Attitudes Scale for parents was good ($\alpha = .75-.85$) in the current sample.

Emotional response following storybook reading and discussion.

The Positive and Negative Affect Scale (PANAS; Watson, Clark, & Tellegen, 1988) is a widely used measure of affect. It is composed of positive and negative affect scales, each with 10 items. Positive affect is a dimension of emotionality that includes alertness and enthusiasm, whereas negative affect reflects subjective distress. A variety of time specifiers (e.g., emotions at the present moment, today, week) have been used in the administration of this scale. Due to the repeated nature of the assessments in this study, participants were asked the extent to which they felt each emotion at “the present moment.” Items were rated on a 5-point Likert-type scale (1 = *very slightly or not at all*, 2 = *a little*, 3 = *moderately*, 4 = *quite a bit*, 5 = *extremely*).

Responses are summed, and scores on each affect scale can range from 10 to 50, with higher scores indicating greater positive or negative affect. In previous studies, the internal consistency reliabilities for the present moment version of the PANAS were 0.89 and 0.85 for the positive and negative scales, respectively (Watson, Clark, & Tellegen, 1988). The PANAS has adequate external validity based on correlations with measures of distress and psychopathology (Watson, Clark, & Tellegen, 1988). Parent reliability on the PANAS was good in the current sample, ranging from $\alpha = .87-.92$ and $\alpha = .77-.93$ for positive and negative affect, respectively.

Willingness to engage in AD approach behavior.

Parents’ willingness to engage in a variety of behaviors in the event that someone close to them had AD was assessed using a scale similar to the one used with children (see Appendix V). The scale consists of 9 items that capture the functional and social behaviors that parents may engage in. Parents rated their willingness to engage in each behavior on a 4-point Likert scale (1

= *not at all*, 2 = *a little bit*, 3 = *quite a bit*, 4 = *a lot*). Responses are summed, and scores range from 9-36, with high scores reflecting greater willingness to interact with people with AD.

Internal consistency for the parent willingness scale in this sample was good ($\alpha = .86-.87$).

Perceived self-competence in discussing Alzheimer's disease.

Parents' self-perceived ability to discuss and model ways of interacting with people with AD was assessed using a scale developed for this study (see Appendix VI). The scale consists of 14 items: one general item about overall ability and 13 items about specific competencies. The items for this instrument were based on suggested topics of discussion for parents provided in other AD storybooks (Frantti, 2002; Pollack & Belviso, 2009; Schnurbush, 2007), as well as from suggestions from the Alzheimer's Association parent and teacher resource list (Alzheimer's Association, 2011). For example, parents were asked to rate how competent they felt discussing AD symptoms, the child's emotions, and stresses that the parent might experience when providing care for someone with AD. The scale utilizes a 4-point Likert-type scale (1 = *not at all competent*, 2 = *somewhat competent*, 3 = *mostly competent*, 4 = *very competent*), with scores ranging from 13 to 52; higher scores indicate greater perceived competence in discussing AD. In the current sample, internal consistency of the parent self-competence scale was good ($\alpha = .92-.94$).

Satisfaction with book and discussion.

Outcomes evaluating parent satisfaction with the storybook were also developed based on questions used in the study by Glang and colleagues (2005) described above. The three questions assess parent satisfaction with the book: "Did you like this book," "Did you understand this book," and "Do you know more about AD after reading the book." Satisfaction questions were rated on a 4-point Likert-type scale (1 = *not at all*, 2 = *a little bit*, 3 = *quite a bit*, 4 = *a lot*).

In addition, parents answered four questions regarding the likelihood of reading this book again to their children and recommending this book to other parents if the children either had, or did not have, a relative or close family friend who was diagnosed with AD. These items were rated on a 4-point Likert-type scale (1 = *not at all likely*, 2 = *somewhat likely*, 3 = *mostly likely*, 4 = *very much likely*).

Following the parent-child discussion about the book, parent satisfaction with the discussion was also measured. Parents responded to three questions regarding the extent to which they liked the discussion with their children and believe the discussion increased their children's, and their own, understanding of AD. The items were assessed using a 4-point Likert-type scale (1 = *not at all*, 2 = *a little bit*, 3 = *quite a bit*, 4 = *a lot*).

Procedure

Given the novelty of many of the instruments used in this study, the procedure and materials were pilot tested with three families. In particular, the length of the complete assessment was confirmed to take between 1-1.5 hours, the clarity and comprehensibility of all outcome measures were examined, and the usefulness of the parent discussion guide was assessed. Pilot participants generally stated that the assessments were clear and reasonable. While the wording of some questions was modified to improve comprehensibility, few major changes were made based on the pilot families. In order to get a child report of AD experience, a question asking whether children had heard of AD was added; an additional question asked parents to indicate how many people with AD their child knew. Five additional questions were added to the child AD knowledge scale. Questions examining the likelihood that parents would reread the book or recommend the book to others if the child did not know someone with AD were added.

Interested participants were screened by telephone to ensure that they met inclusion criteria. Once eligibility was determined, participants were scheduled. All study procedures took place in a comfortable suite in the Clinical Geropsychology laboratory in the Department of Psychology. At the beginning of the session, consent forms were discussed with parents and children, with children providing verbal assent and parents providing written consent for both themselves and their child. Consent included permission to video record parent-child interactions during book-reading and discussion sessions. Video analysis will not be addressed in this manuscript because it is outside the scope of the proposed dissertation.

Data analysis

Descriptive statistics were used to characterize the sample and the outcome measures. Bivariate correlations were conducted and reviewed to inform subsequent analyses. Two repeated-measures multivariate analyses of variance (MANOVAs), one for children and one for parents, were employed to assess the overall effect of the interventions on the outcome measures. The MANOVA for children included the following dependent variables: AD knowledge, attitudes about AD, willingness, positive and negative affect, with time (i.e., reading and discussion phases) being the within-subjects factor. The MANOVA for parents included the following dependent variables: attitudes about AD, willingness, self-competence, and positive and negative affect, with time again serving as the within-subjects factor. Paired-sample t-tests were used to examine significant within-subjects results. Parent AD knowledge was excluded from the parent MANOVA because it was only assessed at two time points, at baseline and after the discussion. A paired-samples t-test was used to examine the effects of the interventions on parent AD knowledge.

Review of data for statistical assumptions

Missing data resulted most often in the parent surveys, with 12 parents having at least one missing data point; only one parent had more than 2 missing data points, with 8. Parents occasionally skipped questions or marked two answers for one question. Three children each had one missing data point. However, there appeared to be no systematic pattern for missed responses. To be certain, a second dataset with imputed data was developed. Imputed scores were calculated using each individual's mean score for the scale the item belonged to, at that time point. For example, the imputed score for a missing item on the attitude scale at T2 was calculated by averaging the other items on the attitude scale at T2. Comparing results between the missing and imputed databases, there were no differences in findings on any of the omnibus or univariate tests. The dataset with imputed data points was used for the multivariate analyses in order to assure adequate power.

Following examination of z-scores for univariate outliers, and Mahalanobis distance and leverage for multivariate outliers, one parent was identified as both a univariate and a multivariate outlier. This parent scored particularly high on negative affect at all three time points and was excluded from the multivariate analyses. None of the children were identified as univariate or multivariate outliers. There were no issues with multicollinearity.

In terms of normality, parent baseline AD knowledge scores were negatively skewed, and negative affect was positively skewed at all three assessment points for both parent and child. Skew improved after undergoing log transformations, so log-transformed data were used in the analyses.

Repeated-measures MANOVA assumes that the intervals between measurements are equally spaced. The study was designed such that time intervals between assessments were equal. Repeated-measures MANOVA also assumes that data are complete for all subjects.

Results

Characteristics of sample

Fifty-five parent-child dyads were recruited for this study (see Table 1). The children ranged in age from 7 years 0 months to 8 years 11 months ($M = 7.89$ years, $SD = .56$) and were in grades 1 to 3. Of the children, nearly half were male ($n = 29$, 53%). The racial diversity of the children was reflective of the population of St. Louis, with 78% White, 22% Black, and 11% Asian (U.S. Census Bureau, 2010). Four children were Hispanic.

Parents ranged in age from 24 to 61 years ($M = 40.51$, $SD = 6.41$). The majority of the parents were female ($n = 46$, 84%). Parent racial background was similar to children, with 2% Native American or Alaska Native, 9% Asian, 20% Black, and 76% White. This distribution reflected the diversity of St. Louis (U.S. Census Bureau, 2010). Two parents identified as Hispanic. The majority of the parents were currently married ($n = 42$, 76%), with the remaining parents divorced ($n = 8$, 15%) or never married ($n = 5$, 9%). Parents in this sample were highly educated: 20 (36%) had attained a bachelor's degree, and 30 (55%) had a post-baccalaureate degree.

Parents reported that they read to their child, on average, 3.1 hours per week ($SD = 2.3$). Parents indicated that children averaged about four hours per week ($SD = 3.9$) reading on their own. Child oral comprehension scores on the CELF-4 ranged from 7 to the maximum 15. The scores were normally distributed with a mean of 11.82 ($SD = 1.98$). According to the CELF-4 normalized scores, a mean score of 11 is a scaled score of 10 (50th percentile) for 7-year-olds and a scaled score of 9 (37th percentile) for 8-year-olds (Semel & Wiig, 2003), suggesting adequate reading comprehension skills among the children in the study.

Child experience with AD was assessed using two methods. In the first, children simply reported whether they had heard of AD. Nearly 80 percent ($n = 43$) of the children indicated that they had *not* heard of AD. Moreover, children who had heard of it often stated that their parent had briefly described the disease in the context of the study visit. Meanwhile, 20 (36%) parents indicated that their child knew at least one person with AD. Parents reported a range of experiences with people with AD. While all parents had heard of AD, few endorsed having a parent or parent-in-law ($n = 5$, 9%) or living with someone who had AD ($n = 4$, 7%). Nearly two-thirds ($n = 34$, 61.8%) reported having a nonparent relative or close family friend with AD. One-third ($n = 18$, 32.7%) indicated that they had worked or done volunteer work with individuals with AD.

Parent scores on the ADKS ranged from 15 to 29 with a mean of 24.1 ($SD = 3.36$).

Child outcomes

See Table 2 for a summary of the means and standard deviations of the child outcome measures. The results for specific outcome measures will be discussed below in more detail. In terms of an omnibus multivariate test, a repeated-measures MANOVA indicated a significant overall effect of the interventions on the child dependent variables, $F(10, 45) = 27.092$, $p < .001$ (see Table 3 for confidence intervals). Post hoc analyses revealed that storybook reading and discussion improved child AD knowledge, $F(2, 108) = 165.525$, $p < .001$, attitudes, $F(2, 108) = 19.395$, $p < .001$, and willingness, $F(2, 108) = 12.169$, $p < .001$, but did not influence positive, $F(2, 108) = 1.512$, $p = .227$, or negative affect, $F(2, 108) = 2.203$, $p = .119$. Specifics about the points at which significant changes occurred will be addressed in subsequent sections. See Figure 2 for a depiction of changes in standardized scores for child outcome measures.

Knowledge about AD.

At baseline, average child performance on the child knowledge scale was 11.64 ($SD = 2.60$) out of a possible 20. This mean score indicates that children were performing at a rate just higher than chance and suggests that any changes that are observed following interventions are true gains in AD knowledge. Scores following book reading and discussion were 15.93 ($SD = 1.61$) and 16.27 ($SD = 1.64$), respectively. Post-hoc paired t-tests revealed that knowledge significantly increased after reading the book, $t(54) = -12.873, p < .001$, but did not increase additionally after the discussion, $t(54) = -1.687, p = .097$ (see Table 3 for confidence intervals).

Qualitatively, children's responses at baseline reflected biases that children may have about many types of illness (e.g., people with AD are not able to do things that they enjoy) and common fears (e.g., young children can catch AD; see Table 4). Although children appeared to benefit from reading the book, showing increased knowledge overall, they continued to misunderstand some facts. While the book specifically mentioned the distinction between AD and senility, 40% of the children responded incorrectly to this item at baseline, 47% after book reading and 44% after the discussion. Children also had difficulty understanding the complexity of the AD diagnostic process and differentiating problems commonly experienced in old age (e.g., poor hearing) from AD symptoms. These items required that children infer information from the book. Discussion did not further clarify facts that children did not comprehend after reading the book.

In general, children reported that they understood the book at high levels, with 45 (82%) indicating that they understood the book "quite a bit" or "a lot." They also reported similarly high levels of subjective AD knowledge gained after reading the book, with 44 (80%) indicating that they learned "quite a bit" or "a lot."

Attitudes about people with AD.

Children had significantly more positive attitudes about AD after reading the book, $t(54) = -4.607, p < .001$ (baseline mean = 27.33, after reading = 30.05). However, attitudes about AD did not become more positive after having the discussion, $t(54) = -.728, p = .470$ (after discussion, mean = 30.40). From a more qualitative perspective, there were some items on which there was noteworthy change. For instance, after reading the storybook, fewer children endorsed feeling uncomfortable with people with AD (53% before versus 33% after reading the book) or scared of people with AD (35% versus 20%). Children were also less likely to believe that people with AD are unable to do things that they want to do (44% before versus 64% after). Children also expressed more positive attitudes about people with AD after reading the storybook, with more children indicating that it could be fun to spend time with people with AD (53% before versus 84% after reading the book). Children's attitudes did not change on other items (e.g., if someone with AD needed help with something I would help them).

Willingness to interact with people with AD.

At baseline, the average children's willingness score was 26.27 ($SD = 5.15$), with mean scores after reading and discussing the storybook of 28.33 ($SD = 5.52$) and 28.44 ($SD = 5.71$), respectively. Scores after reading, $t(54) = -3.731, p < .001$, and discussing, $t(54) = -3.760, p < .001$, the storybook were both significantly higher than baseline, but not significantly different from each other, $t(54) = -.348, p = .729$.

Descriptively, when children were more varied in their willingness to engage in other behaviors at baseline, they were more willing to engage in some behaviors than others after reading the storybook. For instance, more children wanted to spend more time with people with AD (quite a bit/a lot: 51% versus 77%). However, while the proportion of children who indicated that they would want to give someone with AD more hugs and kisses "a lot" increased

from 22% to 38%, the proportion of children who did not want to give this physical support at all did not change (20% before reading versus 22% after reading). Finally, children did not demonstrate greater willingness to do more chores around the house after the interventions, with nearly identical numbers of children willing to do this activity at each time point.

Emotional response.

As described above, there was no change at any time point for positive or negative affect.

Satisfaction with book and discussion.

All but one child reported liking the book at least “a little bit,” and nearly half of the children indicated that they liked reading the book “a lot” ($n = 27, 49\%$). Many children reported that they were “quite likely” ($n = 14, 26\%$) or “very much likely” ($n = 20, 36\%$) to read the storybook again. They also indicated that they would recommend the book to others (e.g., siblings, friends) at roughly the same rate, with the majority of children saying they were “quite likely” ($n = 20, 36\%$) or “very much likely” ($n = 20, 36\%$) to recommend the book. Girls were more likely to indicate interest in reading the book again ($r = .330, p = .014$) and recommending the book to a friend ($r = .354, p = .008$). Finally, children varied in the extent to which they liked the discussion. Five children (9%) indicated that they did not like the discussion at all, 13 (24%) liked the discussion “a little bit,” 8 (15%) “quite a bit,” and the remaining 29 (53%) “a lot.”

Parent outcomes

A repeated-measures MANOVA indicated a significant omnibus multivariate effect of the interventions on the dependent variables, $F(10, 43) = 10.382, p < .001$ (see Table 2 for descriptive statistics). Post-hoc analyses showed significant increases in parent attitudes, $F(2, 104) = 32.955, p < .001$; willingness, $F(2, 104) = 25.150, p < .001$; self-competence; $F(2, 104) = 50.515, p < .001$; and a decrease in negative affect, $F(2, 104) = 5.593, p = .005$, after the

interventions. There was no significant change in parent positive affect, $F(2, 104) = 2.007, p = .154$. Figure 3 presents changes in standardized scores for parent outcome measures.

AD knowledge.

Since we did not expect the interventions to influence scores on the ADKS, the child AD knowledge scale were administered to parents in order to examine whether the interventions had an impact on parent knowledge. Not surprisingly, parents scored nearly at ceiling (maximum score = 20) on the child AD knowledge scale ($M = 18.48, SD = 0.88$) at baseline. Despite performing nearly at ceiling at baseline, there was still a significant increase in knowledge after the discussion ($M = 19.35, SD = 0.73$), $t(53) = -5.643, p < .001$. See Table 3 for confidence intervals. Although most parents correctly answered most items at baseline (see Table 4), some items were more challenging. Knowledge on the following items at baseline improved dramatically: “people with AD cannot help the way they act” (24% incorrect), “people with AD have trouble controlling how they feel” (26% incorrect).

Attitudes about AD.

Prior to reading the storybook, parent attitudes toward people with AD were relatively positive ($M = 111.04$ out of a possible 140, $SD = 12.73$). After the book reading and discussion, the average scores were 117.30 ($SD = 10.65$) and 118.64 ($SD = 12.55$), respectively. Paired t -tests indicated that scores after reading, $t(52) = -5.898, p < .001$, and after the discussion, $t(52) = -6.695, p < .001$, were higher than at baseline, but not different from each other, $t(52) = -1.756, p = .085$.

Willingness to interact with people with AD.

Parents reported relatively high levels of willingness to interact with an individual with AD on a scale with a maximum score of 40 ($M = 29.23, SD = 4.36$). Nevertheless, parent

willingness scores increased after reading the storybook ($M = 30.69$, $SD = 4.29$) though not after the discussion ($M = 30.93$, $SD = 4.41$). Statistically, there was a significant increase in parent willingness to engage in approach behaviors with people with AD compared to baseline after reading the book, $t(52) = -5.401$, $p < .001$, and after the discussion, $t(52) = -5.538$, $p < .001$, but there was no additional increase between reading and the discussion, $t(52) = -1.268$, $p = .210$. Qualitatively, after the interventions, parents appeared more willing to take care of a person with AD or to ask their children to do more chores around the house.

Emotional response.

Mean scores on positive affect at baseline, after reading, and after the discussion were 33.15 ($SD = 7.50$), 33.06 ($SD = 8.41$), and 32.09 ($SD = 9.40$), respectively. As indicated above, post-hoc analyses did not identify an effect of the interventions on parent positive affect. Compared to positive affect scores, average negative affect scores were lower (T1 $M = 11.37$, $SD = 1.98$; T2 $M = 10.76$, $SD = 1.57$; T3 $M = 10.72$, $SD = 1.47$). Scores after reading, $t(52) = 2.588$, $p = .012$, and after discussion, $t(52) = 3.026$, $p = .004$, were lower than baseline, but there was no difference between reading and discussion, $t(52) = .250$, $p = .803$.

Self-competence.

Parent average baseline self-competence score was 34.64 out of a possible 52 ($SD = 9.01$), which increased after reading ($M = 40.89$, $SD = 7.51$) and after the discussion ($M = 42.42$; $SD = 6.68$). Self-competence scores after reading the storybook, $t(52) = -67.169$, $p < .001$, and after the discussion, $t(52) = -8.409$, $p < .001$, were significantly higher than baseline. Unlike the other outcome measures, post-hoc analyses indicated an additional increase in scores following the discussion, $t(52) = -2.413$, $p = .019$. A separate, repeated-measures analysis of variance identified an omnibus effect on another measure of parent self-competence, which was a one-

item parent rating of their overall self-competence, $F(2,52) = 25.312, p < .001$. Post-hoc t-tests indicated a significant increase in parent-perceived self-competence between baseline and book reading, $t(53) = -4.794, p < .001$, but no additional gain after the discussion, $t(53) = -1.737, p = .088$.

Qualitatively, at baseline, parents indicated feeling most competent in providing children with support (see Table 5). Meanwhile, at baseline, parents expressed feeling least competent in discussing how AD is diagnosed and AD treatments. However, parents appeared to feel greater self-confidence in discussing these topics after reading the book and after the discussion. After the discussion, parents indicated greater self-confidence particularly in discussing the changes the child could experience if a loved one had AD, explaining how a child could cope with a loved one's AD, and helping a child talk and interact with someone with AD.

Satisfaction with book and discussion.

The majority of parents indicated that they liked the storybook they had read: 48 (87%) reported that they liked the book “quite a bit” or “a lot.” All of the parents endorsed high understanding of the book, but there was a range of parent responses regarding the extent to which they themselves knew more about AD after reading the storybook to their child. Only 6 parents (11%) indicated that they learned nothing from reading the book.

Parents indicated that they were more likely to reread the storybook with their children or recommend the book to others if the child knew someone with AD. More than one-third of parents indicated that they were “not at all likely” to reread the storybook with their child ($n = 19, 35\%$) or recommend the book to others ($n = 19, 35\%$) if the child did not know anyone with AD. However, all parents reported that they were at least “somewhat likely” to reread the storybook or recommend it to others if the child knew someone with AD.

Half the parents ($n = 29$, 53%) indicated that they liked the discussion “quite a bit” and the majority of parents ($n = 50$, 91%) indicated that the discussion increased their own understanding of AD at least “a little bit.”

Parent education was negatively correlated with the extent to which parents liked the book ($r = -.298$, $p = .029$). Further, being a higher educated parent was associated with a decreased likelihood of rereading the book with their child ($r = -.319$, $p = .019$) and recommending the storybook to others ($r = -.283$, $p = .038$) if the child knew someone with AD. Parent education was also negatively correlated with rereading ($r = -.362$, $p = .007$) and recommending the book ($r = -.376$, $p = .005$) to a child who does not know anyone with AD. Unsurprisingly, parent education ($r = -.312$, $p = .022$) was negatively correlated with how much parents felt the discussion increased their own AD knowledge, such that parents with more education felt the discussion helped their understanding of AD less.

Child experience with AD, as reported by parents, was related to parent response to the storybook and discussion. When the child knew fewer people with AD, parents reported feeling like they themselves knew more about AD after reading the book ($r = -.461$, $p = .001$). Unsurprisingly, the child knowing fewer people with AD was associated with parents feeling that the discussion increased both their child’s ($r = -.327$, $p = .016$) and their own understanding of AD ($r = -.337$, $p = .013$).

Finally, parent experience with AD was associated with their reactions to the book and discussion. Not having a parent or parent-in-law ($r = -.288$, $p = .034$) or a non-parent ($r = -.314$, $p = .021$) with AD was associated with parents feeling that they knew more about AD after reading the book. Additionally, not having a parent or parent-in-law with AD was associated with parents feeling that they themselves had a better understanding of AD after the discussion (r

= $-.308$, $p = .023$). As a whole, parents, who endorsed greater benefits of the book, were more likely to have less education and less experience with individuals with AD; their children were also less likely to have interacted with individuals with AD.

Exploratory Analyses

The following post-hoc correlational tests examined some of the interesting results. See Tables 6 and 7 for child and parent correlations, respectively. Given the exploratory nature and the potential for Type I error when conducting multiple correlations, the following data should be interpreted with caution. If Bonferroni corrections were used as a more stringent cut-off for significance, only p values less than $.001$ would be interpreted. However, for the sake of discussing potential questions that arise from this data, I am presenting the following findings. In addition, these preliminary data may stimulate areas of future study.

Child outcomes.

Child gender was positively correlated with child willingness to interact with people with AD at all measurement points, such that girls were more willing to engage with people (T1: $r = .293$, $p = .030$; T2: $r = .289$, $p = .032$; T3: $r = .350$, $p = .009$). A post-hoc repeated-measures analysis of variance indicated a between-subjects effect, such that girls endorsed greater willingness to interact with individuals with AD than boys, $F(1,53) = 56.828$, $p = .012$. There was no interaction between child gender and time, $F(2, 52) = .880$, $p = .421$.

Parent pre-existing AD knowledge, as measured by the ADKS, was related to child outcomes after the discussion, but not after reading. Higher parent education was associated with more negative child attitudes about AD ($r = -.349$, $p = .009$) and greater negative affect after the discussion ($r = .285$, $p = .035$).

Parent work experience was related to some of the children's responses to AD. First, parent work experience was negatively associated with child attitude such that children whose parents did not have work experience with AD individuals had more positive attitudes about AD after reading ($r = -.352, p = .008$) and discussing the book ($r = -.349, p = .009$). Parent AD work experience was associated with less child willingness to interact with people with AD both at baseline ($r = -.288, p = .033$) and after reading the storybook ($r = -.289, p = .032$). Further, parent AD job experience was negatively correlated with positive affect at baseline ($r = -.340, p = .011$), such that children with parents who had worked with people with AD had lower positive affect. Thus, parent AD work experience appears to be negatively associated with children's attitudes, willingness to engage with people with AD, and feelings.

Parent outcomes.

Child age was positively associated with parent self-competence at baseline, ($r = .379, p = .011$), after reading the storybook ($r = .469, p = .001$), and after the discussion ($r = .552, p < .001$), such that parents with older children tended to feel more competent. According to post-hoc analyses of covariance, the effect of the interventions on self-competence disappeared when covarying out child age, $F(2,41) = 1.291, p = .284$.

The pre-existing AD knowledge that parents brought into the session was related to their attitudes about AD at all time points (T1: $r = .328, p = .015$, T2: $r = .425, p = .001$, T3: $r = .374, p = .005$), such that parents with higher scores on the ADKS had more positive attitudes. These results may be an artifact of the type of people who were interested in participating in the study.

Prior parent experience with AD was associated with several of the parent outcomes. Having work experience was associated with more positive parent attitudes about AD throughout the study (T1 $r = .472, p < .001$; T2 $r = .449, p = .001$; T3 $r = .407, p = .002$). A post-hoc

repeated measures analysis of variance revealed no interaction between time and job, $F(2, 51) = .692, p = .505$. Therefore, rates of AD attitude change did not differ for parents with AD work experience compared to those without experience. Rather, parents with AD work experience had higher scores than those who did not, $F(1, 52) = 14.810, p = < .001$.

Meanwhile, parents reported a benefit of work or volunteer experience; parents with these experiences tended to indicate greater perceived self-competence in discussing AD with their children at baseline ($r = .296, p = .030$) and after discussing the storybook ($r = .345, p = .011$). A post-hoc repeated measures analysis of variance indicated that parent AD job experience did not differentially affect self-competence after the interventions, $F(2, 51) = .672, p = .515$. Rather, parents with AD work experience had more perceived self-competence than those who did not, $F(1, 52) = 6.291, p = .015$. Thus, parents with AD job experience did not appear to gain self-competence at a different rate than those without job experience. In sum, parents with AD work or volunteer experience appear to have greater perceived self-competence in discussing AD with children, but their prior experience does not influence the amount of self-competence they gain as a result of the interventions and their children had more negative attitudes about AD and were less willing to interact with people with AD.

Discussion

Overall effects

The goal of this study was to examine the effects of storybooks on child and parent Alzheimer's disease-related knowledge, attitudes, behaviors, and emotions. Consistent with Social Cognitive Theory (SCT), the findings from this study suggest that when parents and children read a storybook about AD together it enhances their knowledge and shifts their

attitudes about AD, although further discussion after reading prompts few additional changes. The one exception is that parent self-competence in discussing AD with children improves after both reading and discussion. Although child positive and negative affect or parent positive affect do not change, parent negative affect decreases after book reading and stays lower after the discussion. This is the first empirical study to document the benefits of reading storybooks about dementia to children, an activity that has been advocated by several dementia organizations, including the Alzheimer's Association. Further findings and implications are discussed below.

Effects on children

Consistent with my hypothesis, reading the AD storybook results in small increases in children's knowledge, slightly more positive attitudes about AD, and greater willingness to interact with people with AD. While children in this study had misconceptions about AD at baseline, which reflects misunderstandings of illness that are typical of young children (Bibace, 1980; Kalish, 1996, 1998), these misconceptions abate after reading the book. This finding suggests that, much like other bibliotherapy for children, books about AD have the potential to correct children's misconceptions about AD, which may subsequently reduce the fears and stigma they have about the disease and people who have it (e.g., Bauer, 1985). After reading this storybook, children gained an understanding that people with AD cannot help the way they act, that people with AD can do things that they enjoy, and that there are productive ways children can spend time with people with AD. On the other hand, children continue to demonstrate misconceptions about the disease regarding facts not addressed directly by the book, suggesting that storybooks need to be comprehensive in their coverage. For example, unless explicitly told otherwise, children continue to see little difference between AD and normal aging. Further, it is possible that children may benefit most when facts are discussed explicitly in the storybook, such

as through dialogue between characters. Indeed, some researchers suggest that skills are best developed when models express their line of thinking aloud (Bandura, 1986). Finally, children demonstrate not only objective improvement in AD knowledge but also subjectively describe greater AD knowledge after reading the book, which may result in greater self-efficacy in behaviors that support people with AD, as predicted by SCT.

In this sample, children's attitudes about AD began relatively positive and became more positive after reading the storybook. When attitudes did not change, it may have been because children tended to have positive attitudes on these items at baseline, which may have limited their potential to become more positive. Similarly, children's willingness to interact with people with AD was relatively high at baseline and improved after reading the book, particularly for activities that were depicted in the storybook compared to activities that were not (e.g., spending more time with people with AD versus doing more chores around the house). Thus, the types of activities depicted in the storybooks may have played a role in children's willingness to interact with people with AD. While qualitative, this preliminary finding is consistent with the social cognitive framework (see below for additional discussion), future studies could examine this result experimentally to determine the extent to which activities in a storybook influence the willingness of children to engage in the same behaviors.

Contrary to my predictions, neither negative nor positive affect changed after reading or discussing the storybook. These results suggest that the book did not cause distress among the young children, even though it depicted odd behaviors and emotional responses in an individual with AD. The child character in the book may also have influenced children's emotional reactions. In this book the child experiences a number of emotions, both positive and negative, during the course of the book, but she comes to accept her grandmother's disease and the

resolution is mostly positive. Similarly, children who read the book may resolve their own mixed emotions by the end of the book. Future studies can examine more specifically whether certain parts of the book (e.g., child noticing odd behaviors, learning the diagnosis, etc.) elicit specific emotions from children.

Effects on parents

The book reading and discussion were beneficial in the same ways for parents as they were for children, and results were generally consistent with my hypotheses. In this highly educated sample of parents, parents had substantial knowledge about AD even before reading the storybook, but still gained knowledge at follow-up after the discussion. Meanwhile, parents subjectively felt they knew more after the discussion, which could have been the result of using a discussion guide or teaching during the discussion, which is consistent with the teaching literature. Improved parent performance, both objective and subjective, suggests that parents can themselves gain knowledge, even from a children's book.

Parents also had more positive attitudes and were more willing to interact with people with AD after reading the storybook. Like children, parents expressed more interest in learning more about AD, though they were less willing to take on other activities that may require greater investment of time or resources, such as taking care of a person with AD. While interested in some involvement with people with AD, parents who already have childcare responsibilities may recognize the practical commitment of caring for someone with AD and resist additional responsibilities. Qualitatively, parents also were initially reluctant to ask children to help around the house but became more willing to ask after reading and discussing the book. It is possible that observing the child character's willingness to do chores and the parent characters asking children to take on more responsibilities normalizes children helping with chores. In addition,

parents may feel more comfortable asking children to do more chores after they have talked to their children and hear that children themselves are willing to help.

As with the children, parents' positive affect was not affected by the interventions, and negative affect decreased after reading the storybook. While parents reported less confidence in the more AD-specific tasks (e.g., discussing how AD is diagnosed) at baseline, they expressed greater confidence following both interventions. That parents feel more confident in their abilities after the discussion is consistent with research suggesting that teaching information to others can have many benefits (McKeachie, 2006). Thus, parents' level of confidence may rise from teaching and discussing information about dementia. Future studies could try to isolate what aspects of the discussion most help parents.

Satisfaction with the storybook and discussion

Children and parents, in particular, both reported liking the storybook. Children responded positively to the book suggesting that, despite the potentially difficult nature of the content, it is possible to present challenging material to children in an effective and engaging way using accessible language and humor. Meanwhile, parents found the book useful and were most likely to reread the book or recommend it to others when the child knew someone with AD. While both parents and children acknowledged liking the discussion, children were slightly less enthusiastic about the discussion. This response may be associated with children's tiredness at this point in their visit. It is also possible that the discussion of the book was unnatural and did not parallel the types of conversations children would normally have with their parents when reading a storybook. I address this topic further below.

Exploratory analyses suggest that parents who benefit most from storybooks and subsequent discussions may have characteristics that put them at a disadvantage (e.g., less

education or experience) for discussing AD with their children. For example, parents with less education and lower pre-existing AD knowledge scores indicated a greater perceived increase in knowledge about AD after reading the book. These same parents were also more likely to reread the book with their child or recommend the book to others. Parents with less knowledge or AD experience, in particular, may view these storybooks as tools that facilitate conversations about AD with their children.

Evaluation and Recommendations for AD storybooks

Social-cognitive theory (SCT) can guide evaluation of AD storybooks because it specifies factors that can contribute to behavior change. First, according to SCT, people must have knowledge before enacting behavior change. My study suggests that an AD storybook can increase child and parent knowledge and decrease children's misunderstandings of AD. But, books must provide accurate information if people are to understand the benefits and consequences of different health practices (Sharma & Romas, 2012). As noted earlier, there are over 30 storybooks about dementia available in the marketplace, and they range widely in their content. Therefore, future studies could examine the accuracy of these storybooks.

Second, SCT suggests that models can guide behavior (Bandura, 1977, 1986), and my study shows that book reading increases child and parent attitudes and willingness to engage in prosocial behaviors toward people with dementia. Here again, future research could use SCT as a framework for evaluating the importance of incorporating models in storybooks that are diverse in age, gender, ethnicity, and AD experience, among other attributes. For example, though preliminary, my post-hoc tests found that being a girl was associated with greater willingness to engage with people with AD. It is possible that the depiction of the protagonist as a young girl contributes to this effect, which would be consistent with SCT. Currently, girl and boy child

characters are relatively evenly represented in AD storybooks, while ethnic diversity is limited and currently does not reflect the diversity of the population (Sakai, Carpenter, & Rieger, 2013). Examining the effect of these characteristics on readers could lead to the development of a wider variety of storybooks available to children and parents. In addition, some researchers suggest that animal characters can be used to introduce children to a difficult subject by creating some psychological distance for them (Berns, 2004). Examining whether child or animal storybook characters are more effective at relaying information to children may also be beneficial. It is possible that these different types of characters could serve different purposes for children, either by distancing them from the difficult topic or helping them engage further.

Further, given that the positive behaviors in the books are often reinforced (e.g., parents encourage the child to spend more time with the person with AD), the behaviors and activities that the characters in the books do could influence those that children reading the books engage in. Thus, authors should carefully consider the types of behaviors and activities that they depict in the storybooks. Authors in other AD storybooks often show children creating a memory book or box with the person with AD or looking through a photo album, which likely are attempts to show children how they can cope with the memory issues of the person with AD. These activities are consistent with those suggested by major Alzheimer's disease organizations. However, portraying a greater diversity of activities and coping strategies in these storybooks could provide children and parents with more ideas. After all, many young caregivers take on a wide variety of responsibilities and activities (Fruhauf & Orel, 2008).

Clinical Implications

Bandura (2004) suggests that successful health promotion programs for children should provide information, develop skills that enable the child to translate concerns into effective

behaviors (e.g., through modeling), establish a sense of self-efficacy in the face of challenges, and create a support network. The current study suggests that AD storybooks can, indeed, be beneficial tools to both children and parents. Storybooks appear to improve knowledge, attitudes, and willingness to interact with people with AD, while triggering no increased distress, which supports recommendations from organizations such as the Alzheimer's Association to read storybooks about AD to children. Further, given the relatively high child and parent satisfaction with the storybook, it follows that storybooks can be reasonable tools for discussing AD with young children.

Storybooks can also model appropriate ways of interacting with people with AD at two levels: 1) children reading the book see child characters learn by observing parent characters (indirect), and 2) children and parents reading the storybooks learn vicariously by observing characters in the books (direct). Children reading the storybooks then have two potential routes for learning how to interact appropriately with people with AD, an indirect route when affiliating with child characters observing parent characters and a more direct one when observing child characters. Thus, SCT suggests that experience with individuals with AD, whether through observation or first-hand experience, can guide future behaviors. Indeed, one study found that children who provided more care to grandparents with dementia had more positive attitudes about assisting older adults with long-term care in the future (Hamill, 2012). Likewise, parents may observe the behaviors employed by parents in the storybooks and use them in their interactions with their own children. For example, they may see a parent in a story gently redirect the confused person with AD and subsequently demonstrate this behavior for their own children.

While children and parents may initially feel some uncertainty about interacting with people with AD, according to SCT, vicarious learning can increase self-confidence and lead to behavior change. Children with greater confidence in their ability to interact with people with AD may be more likely to engage in approach behaviors (e.g., spending time with people with AD) and parents may be more likely to reinforce these behaviors. Further, increased self-confidence may translate to increased parent modeling of appropriate behaviors for their children.

Given their common use in daily family life, storybooks may be a useful source of health promotion. Further, since AD affects the family unit and children's understanding of illness are heavily influenced by the family social context (McIntosh, Stephens, & Lyons, 2013), storybooks may be particularly beneficial in AD education because they are commonly used in the family context (e.g., many families read together before bedtime).

Finally, exploratory analyses propose a potential role of demographic characteristics and AD experiences that may influence the effectiveness of AD books. While, the storybook used in this study was written for children ages 5+, it is unclear whether reading a storybook about AD to a 5-year-old child is useful. Given that the 7- and 8-year-old children in this sample gained an understanding of AD from reading this book without emotional distress, it seems that these types of books are appropriate for children of this age. In addition, since vicarious learning is also more likely to occur if observers believe that the outcome is applicable to their specific situations (Bandura, 1977), children and parents with AD experience (e.g., those with family members with AD) may be more invested and, subsequently, more likely to learn from these storybooks. In this sample, parent work or volunteer experience was associated with several negative child outcomes. Parents with greater AD experience may have been themselves interested in

participating. Indeed, children whose parents worked with individuals with AD came to the session with lower positive affect than those who did not, suggesting a preexisting perception of AD or pressure to participate in the study. In addition, it is possible that parents with more AD experience responded differently during the course of the session. For example, these parents may push their own AD knowledge onto their children by providing the child information about AD rather than including the child in the conversation, which may incite resistance in children. While beyond the scope of this study, video analysis of the discussion sessions may lend support to this hypothesis. In contrast, greater previous AD knowledge or AD work experience was generally associated with positive parent outcomes (e.g., higher positive affect and greater self-competence). It may suggest that parents with AD experience may approach discussion of AD with their children differently from parents who do not have this experience. More specifically, these parents may view discussion of AD as an opportunity to impart their knowledge and expertise onto their child. Thus, these preliminary findings suggest that child and parent characteristics may be associated with how children and parents respond to the storybook and discussion. At the same time, given the small sample size and the exploratory nature of these analyses, these findings should be considered cautiously. Future studies should further examine these hypotheses.

Limitations

Given the relative novelty of this study, it is not without limitations. One concern is the poor internal consistency of some of the assessments (e.g., AD knowledge scales, child attitude scale), which may suggest that the tools are not measuring a unified construct. Among children, reliability on the child AD knowledge scale was poor, with Cronbach alpha ranging from -.113 to .376. It is possible that the knowledge scale is not internally consistent because the items

assess knowledge across many different domains of AD. Low internal consistency likely reflects the fact that people, particularly young children, know singular facts about AD but have a level of overall knowledge that differs from person to person. However, the child AD knowledge scale should have good face validity because it was developed based on information in the storybook. Meanwhile, Cronbach's alpha for the child attitudes about Alzheimer's scale was .20 at baseline but .64 and .68 at the other assessment time points. Revising the items on the scale such that there is greater interrelatedness among items to reflect a more homogenous construct may improve internal consistency. At the same time, it is possible, that, like the knowledge scales, the attitude scale addresses a range of distinct attitudes about Alzheimer's disease. It is also possible that, particularly at baseline when children have a less unified concept of AD, their attitudes are less cohesive.

Since the assessments generally had good face validity, it is possible that participants responded in a socially desirable manner. Indeed, both child and parent attitude and willingness scores were relatively high at baseline. While social desirability may have contributed to high baseline scores, if children and parents were responding in a socially desirable manner, it is likely that knowledge, attitude, and willingness scores would have been high at all three assessment points and would not have increased after intervention. It is also possible that participants, aware of the design of the project, are responding to demand characteristics.

Given that this is one of the first studies of its kind, there were few well-validated instruments for the outcomes and many of the assessments used to evaluate the outcome measures were developed for the purpose of the study. For example, the child AD knowledge scale was based on the storybook utilized in this study. While the questions on this scale reflected the expansive scope of AD in the storybook, it is possible that some aspects of the

disease were not captured in the knowledge scale since some questions were specific to the storybook, which could decrease the validity and generalizability of the results. Thus, a few of the questions may have examined children's reading comprehension rather than true knowledge of AD.

Another consideration is the accuracy of the information provided in the storybook. While the storybook used in this study was chosen because of its comprehensive approach to portraying AD, it is possible that the book may have provided some misleading information. For example, it indicated that x-rays are used to diagnosis AD. It is unclear whether the author inadvertently provided incorrect information or intentionally attempted to describe assessments in an accessible way for children. Nonetheless, misconceptions in storybooks can be adopted by readers, leading to subsequently uninformed or incorrect views or decisions. This highlights the necessity for storybooks that provide accurate, yet still accessible, information that addresses a variety of the issues experienced by young children interacting with someone with AD. It may not be feasible for one, single book to capture the diversity of issues a child may be exposed to, and the best option for parents may be to use several books that capture varied experiences.

Another consideration is the measurement of emotional response. While storybooks like the one used in this study may not trigger a strong emotional response in children, it is possible that the PANAS and PANAS-C might not capture all emotional aspects of the experience that parents and children have in the context of reading about AD (e.g., confusion, hope, etc.). For example, questions addressing how children believe they would feel in the hypothetical situation in which their own grandparent has AD may be additional information about how these storybooks might affect emotional response.

It is also possible that the design of the study (e.g., reading first, then discussion) may not be ecologically valid. This design was chosen in order to examine whether the discussion resulted in an additional benefit over the storybook. However, it is possible that this arrangement does not reflect the common interaction between children and parents when they read storybooks together or apart. It is more likely that parents and children are discussing storybooks together as they read them, particularly when the content is unfamiliar. The artificial situation in this study may have contributed to the lack of benefit seen from the discussion. Indeed, a number of studies support the use of shared reading (Hudson & Test, 2011; Justice & Lankford, 2002; Whitehurst, et al., 1988). Future studies might examine which of the following interventions is most effective: 1) reading with no discussion, 2) reading followed by discussion, 3) combined reading and discussion.

In addition the characteristics of the sample may reflect a selectivity bias. Parents in this sample were highly educated, with the great majority having at least a bachelor's degree. Parents who are interested in exposing their children to new information or experiences may be particularly invested in participating in this type of study, thus limiting the generalizability of the findings and potentially reducing the strength of the relationships between variables. Thus, further examination of a more diversely educated population is needed.

Finally, while the interventions, particularly the storybook reading, resulted in significant changes in the directions hypothesized, the size of the effects was small (Cumming & Finch, 2005). One way to improve effect size is to create more psychometrically sound measures of the outcome variables. Further, the motivation for participating in this study is unknown (e.g., parent interest in AD, compensation, etc.). Effects may be larger if the interventions were assessed in a sample with a specific interest in increasing knowledge about AD. Assuming that

people with AD experience (e.g., if the child and parent know someone with AD) are more motivated to learn about AD, the effects of the interventions may be stronger if groups with and without AD experience are compared.

Future directions

While there were limitations to this study, particularly given the novelty of the research in this area, these limitations may inform further research in both design and clinical advancement. First, development of this study highlighted the need for assessments that can be used to examine child knowledge and attitudes about AD. The evaluation of AD knowledge and attitudes has focused on adults and care providers (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009; O'Connor & McFadden, 2010; Lundquist & Ready, 2008), and assessment of child knowledge and attitudes toward AD has been ignored. It would be useful to develop psychometrically sound assessments of child AD knowledge, attitudes, and willingness for use in future research.

In addition, it is possible that certain aspects of the books are particularly useful for parents and children. Future studies should examine the specific components of the storybooks that are most useful to parents (e.g., AD symptoms, talking with a child about AD, types of activities to do with someone with AD). Increased understanding of these components can inform production of books that can help parents better address their children's questions about AD. For example, one study suggests that information that allows people to understand the person with dementia and coping strategies are potentially more useful than didactic information about the disease (Marriott, 2003). In addition, studies can examine the types of information parents are willing to tell their children about AD. Storybooks could be written to address these specific topics.

Social Cognitive Theory provides guidance regarding the specific elements that would make storybooks effective. In addition, SCT suggests that people are more likely to engage in behaviors when a model is more similar to them; thus, matching the gender of the character with the child reading the book may be more effective. In one study (Bell & Morgan, 2000), girls indicated more positive behavioral intentions when the obese child was a girl and boys demonstrated a parallel tendency. Since the child portrayed in the AD storybook is a girl, young girls may respond to this main character differently than boys and be more likely to interact with people with AD after exposure to that model. At the same time, the literature suggests that female children tend to be more empathic and prosocial than male children (Eagly, 2009; Eisenberg, 1989). Several other storybooks on the market have male protagonists, and future studies could examine whether the gender of the child character matters.

Future studies could also examine how characteristics of the participants affect outcomes. Further examination of the effect of child age on various outcomes has implications on health literacy recommendations, such as identifying the appropriate age for parents to begin discussions about AD with young children, particularly since parents sometimes attempt to shield children from health information (Wolf, et al., 2009). Future research should evaluate the age at which discussions about AD is appropriate for young children. In addition, exploratory findings suggest that the more familiar the parent is with AD, based on prior AD knowledge or parent work or volunteer experience, the more negative child outcomes (e.g., less positive attitudes, greater negative affect, decreased positive affect, less willingness). This counterintuitive finding may reflect more on the parents who enrolled their child in this study than the children themselves. Future studies should address the role of child and parent AD experience on the outcomes.

Ultimately, how AD information is relayed to young children may be just as important as what information is given. Parents with an AD background may need to be mindful of the way in which they present information to children (e.g., avoiding jargon) to maximize the children's receptiveness to the information. Observational analyses of the parent-child interactions during storybook reading may identify different parent communication styles and determine whether these styles affect child receptivity to information.

Beyond examination of the storybook, future studies should examine the applied benefits of storybooks within the context of AD health education. While child self-competence was not examined in this study, future studies may examine the extent to which children are confident in their abilities to interact with individuals with AD. For example, a study could examine how reading an AD book compares with carrying out a task with a person with AD in addition to reading the book. SCT would predict that observing other children performing these behaviors may increase the reader's own abilities. Finally, future studies can examine the application of these storybooks not only to people's intentions but also to their actions. For example, do children follow through on behaviors if someone they know is diagnosed with AD? Further, longitudinal studies can help verify long-term effects of these interventions, thereby refuting the potential that findings are due to demand characteristics and social desirability. Thus, longitudinal studies can ultimately evaluate the potentially lifelong impact that these storybooks can have on young children.

Conclusion

Given the growing prevalence of Alzheimer's disease, young children are likely to interact with a grandparent or great-grandparent with AD. However, there has been little research examining how AD affects children and what interventions may be beneficial for them.

Bibliotherapy can be a useful intervention to educate children about dementia, given its ability to introduce difficult topics. The results of the current study suggest that storybooks are, in fact, an effective intervention for increasing knowledge and stimulating attitudinal and behavioral changes when utilized to educate young children and their parents about AD. As the first experimental study to assess the effect of an educational intervention on young children in the context of AD, the study has implications on how and what types of information children are given, as well as how children understand and cope with AD.

Figure 1

Study procedure for children and parents, including two interventions and three assessment points

	T1		T2		T3
Child	<ul style="list-style-type: none"> • Demographics • Reading experience • Reading comprehension • AD experience 	Read Book		Discussion	
	<ul style="list-style-type: none"> • AD knowledge • Attitudes about AD • Emotional response • Willingness 		<ul style="list-style-type: none"> • AD knowledge • Attitudes about AD • Emotional response • Willingness • Satisfaction with book 		<ul style="list-style-type: none"> • AD knowledge • Attitudes about AD • Emotional response • Willingness • Satisfaction with discussion
Parent	<ul style="list-style-type: none"> • Demographics • Reading experience • AD experience • ADKS 	Read Book		Discussion	
	<ul style="list-style-type: none"> • AD knowledge • Attitudes about AD • Emotional response • Willingness • Self-competence in ability to discuss AD 		<ul style="list-style-type: none"> • Attitudes about AD • Emotional response • Willingness • Self-competence in ability to discuss AD • Satisfaction with book 		<ul style="list-style-type: none"> • AD knowledge • Attitudes about AD • Emotional response • Willingness • Self-competence in ability to discuss AD • Satisfaction with discussion

Figure 2

Standardized scores for child Alzheimer's disease knowledge, attitudes, willingness, positive, and negative affect

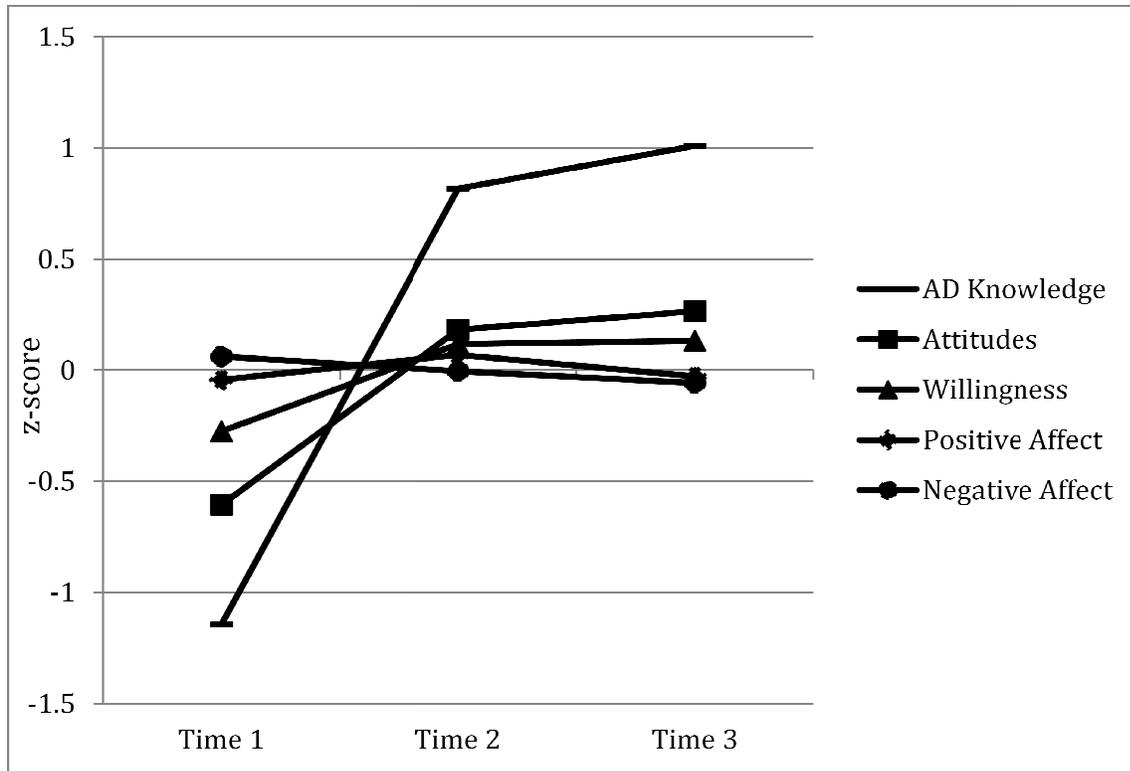


Figure 3

Standardized scores for parent Alzheimer's disease knowledge, attitudes, willingness, positive, and negative affect

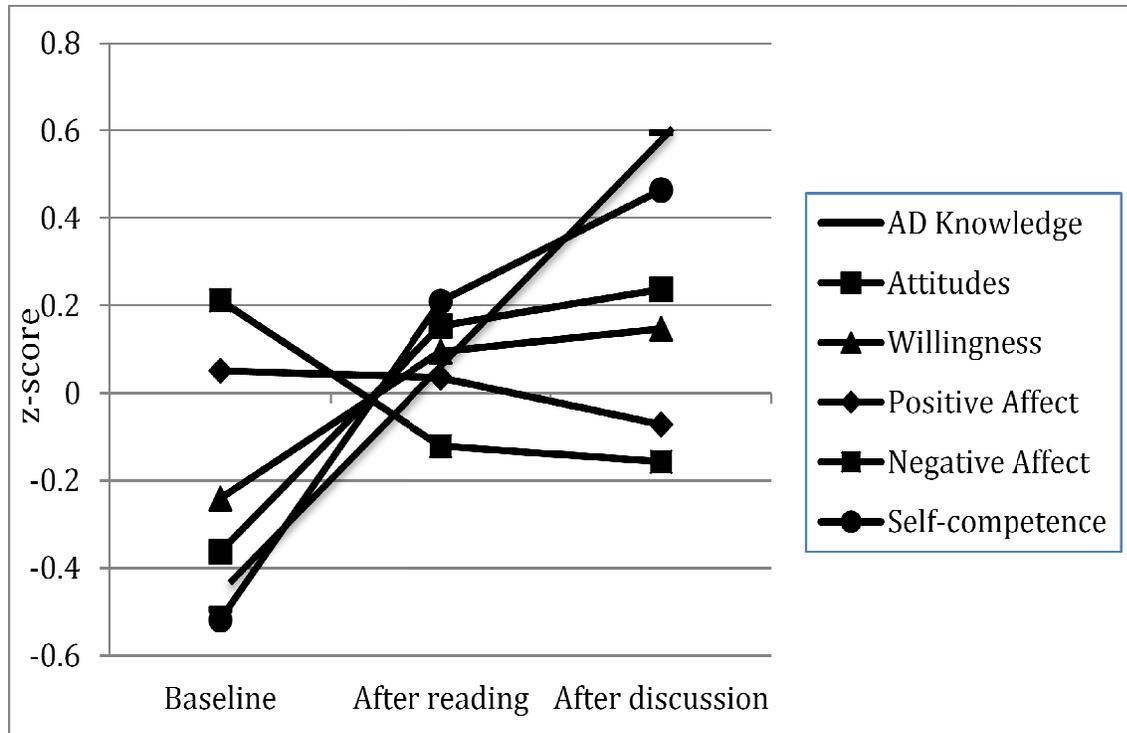


Table 1

Characteristics of the sample

Characteristics	Child		Parent	
	<i>M / n</i>	<i>SD / %</i>	<i>M / n</i>	<i>SD / %</i>
Age, <i>M (SD)</i>	7.89	.56	40.51	6.41
Female, <i>n (%)</i>	29	52.7	46	83.6
Ethnicity, <i>n (%)</i>				
American Indian or Alaska Native	0	0	1	1.8
Asian	6	10.9	5	9.1
Black	12	21.8	11	20.0
White	43	78.2	42	76.4
Hispanic, <i>n (%)</i>	4	7.3	2	3.6
Education, <i>n (%)</i>				
High school			4	7.3
Associate's/Bachelor's			21	38.2
Master's			23	41.8
Doctoral			7	12.7
Marital Status, <i>n (%)</i>				
Single (never married)			5	9.1
Married			42	76.4
Divorced			8	14.5

Note. Sum may not equal 100% because some participants identified with more than one ethnic background.

Table 2

Means and standard deviations for child and parent outcomes

	Children						Parents					
	Time 1		Time 2		Time 3		Time 1		Time 2		Time 3	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
AD Knowledge	11.64	2.60	15.93	1.61	16.27	1.64	18.48	0.88			19.35	0.73
Attitudes	27.33	3.19	30.05	4.34	30.40	4.28	111.04	12.73	117.30	10.65	118.64	12.55
Willingness	26.27	5.15	28.33	5.52	28.44	5.71	29.23	4.36	30.69	4.29	30.93	4.41
Positive Affect	16.67	5.88	17.36	6.28	16.73	6.96	33.15	7.50	33.06	8.41	32.09	9.40
Negative Affect	8.51	4.04	8.24	3.78	8.02	4.19	11.37	1.98	10.76	1.57	10.72	1.47
Self-competence	--	--	--	--	--	--	34.64	9.01	40.89	7.51	42.42	6.68

Note. The potential ranges for child outcomes are AD Knowledge 0-20, Attitudes 10-40, Willingness 9-36, Positive affect 5-25, Negative affect 5-25. The potential ranges for parent outcomes are AD Knowledge 0-20, Attitudes 20-140, Willingness 9-36, Positive affect 10-50, Negative affect 10-50, Self-competence 13-52.

Table 3

Confidence intervals of mean differences for child and parent outcomes

	Children						Parents					
	T1-T2		T2-T3		T1-T3		T1-T2		T2-T3		T1-T3	
	<i>LL</i>	<i>UL</i>	<i>LL</i>	<i>UL</i>	<i>LL</i>	<i>UL</i>	<i>LL</i>	<i>UL</i>	<i>LL</i>	<i>UL</i>	<i>LL</i>	<i>UL</i>
AD Knowledge	-5.02	-3.67	-0.68	.06	-5.35	-3.96	--	--	--	--	-1.18	-0.56
Attitudes	-3.91	-1.54	-1.30	0.61	-4.17	-1.97	-8.40	-4.13	-2.87	0.19	-9.88	-5.32
Willingness	-3.16	-0.95	-0.74	0.52	-3.32	-1.01	-2.00	-0.92	-0.61	0.14	-2.13	-1.08
Positive Affect												
Negative Affect							0.01	0.04	-0.01	0.02	0.01	0.04
Self-competence	--	--	--	--	--	--	-7.99	-4.50	-2.80	-0.26	-9.63	-5.92

Note. Confidence intervals not displayed in this table were not significant.

Table 4

Percentage of incorrect child and parent responses on child Alzheimer's disease knowledge scale

	Children			Parents	
	Time 1	Time 2	Time 3	Time 1	Time 3
Average total incorrect	42	20	19	8	3
There is a cure for AD.	69	46	38	2	4
Young children can get AD.	66	35	38	4	0
It is hard for doctors to know if someone has AD.	64	42	35	50	28
People with AD have pain in their hands and fingers.	64	27	27	6	7
People can catch AD from someone who has it.	60	4	6	0	2
Children should not spend time with people with AD.	60	9	4	0	0
People with AD are not able to do things that they enjoy.	58	35	38	7	4
People with AD cannot hear as well as other people who are the same age.	56	36	36	4	0
People with AD cannot help the way they act.	51	4	4	24	0
Having AD is the same thing as becoming senile.	40	47	44	9	9
People with AD sometimes may not trust other people.	40	20	13	0	0
Sometimes people with AD get lost.	35	11	9	0	0
People can have AD but still be physically healthy.	35	6	6	0	0
Doctors only need to do one test to know whether someone has AD.	33	9	7	2	4
Medicine can help people with AD.	24	27	26	9	6
People with AD may accidentally do dangerous things.	24	15	11	2	0
People with AD have trouble controlling how they feel.	24	7	13	26	2
One person with AD may have different problems than another person with AD.	22	16	18	4	0
People with AD have problems with memory.	18	7	0	0	0
People who take care of someone with AD need a break sometimes.	16	6	2	0	0

Table 5

Percentage of parents endorsing each level of self-competence

	Time 1				Time 2				Time 3			
	1	2	3	4	1	2	3	4	1	2	3	4
Overall subjective rating	6	39	39	17	0	22	50	28	0	11	57	32
Discussing AD symptoms	11	44	30	15	2	33	43	22	2	22	46	30
Discussing how AD is diagnosed	48	30	13	9	11	42	28	19	11	32	36	22
Discussing AD treatments	50	30	9	11	24	41	22	13	26	26	32	17
Discussing potential changes in the child's life	9	39	33	19	0	20	39	41	0	7	50	43
Discussing the feelings that someone with AD may have	17	43	24	17	4	19	48	30	2	7	54	37
Discussing stresses parents may experience	11	30	35	24	0	17	44	39	0	13	44	43
Discussing child's emotions or feelings about AD	4	28	35	33	0	13	39	48	0	7	41	52
Discussing what the child can tell friends about AD	7	20	41	32	0	11	46	43	2	11	35	52
Discussing how the child can interact with someone with AD	4	30	39	28	0	13	39	48	0	11	41	48
Showing the child how to talk and act with someone with AD	11	33	32	24	2	11	43	44	0	4	48	48
Helping the child talk and act with someone with AD	4	32	39	26	2	7	43	48	0	4	44	52
Discussing how the child can cope with AD	4	33	37	26	2	9	43	46	0	4	41	56
Providing support to the child	0	6	20	74	0	2	17	82	0	0	19	82

Note. Parent rating of self-competence: 1 = Not at all competent, 2 = Somewhat competent, 3 = Mostly competent, 4 = Very competent.

Table 6

Correlations between child and parent demographics and child outcomes

	Children				Parents								
	Age	Gen	Grade	AD#	Age	Gen	Educ	Mar	ADpar	ADnonLived	ADJob	ADKS	
Baseline													
AD Knowledge	-.105	.203	-.165	-.097	.041	.037	.252	-.064	.094	-.215	-.020	-.043	-.029
Attitudes	.249	.121	.283*	-.186	-.083	.202	-.058	.111	-.113	-.179	-.162	-.134	-.213
Willingness	-.072	.293*	-.064	-.203	-.214	-.034	-.189	.025	-.252	-.171	-.097	-.288*	.029
Positive Affect	.047	.047	.029	-.001	-.128	.110	-.064	-.283*	-.286*	.044	.040	-.340*	-.147
Negative Affect	-.072	.048	-.023	-.177	-.257	-.214	.092	.140	.165	.144	.082	.196	.112
After Reading													
AD Knowledge	.131	.071	.022	-.010	.244	.072	-.135	.044	.014	-.247	-.207	-.041	.211
Attitudes	.198	-.039	.256	-.034	.070	.223	.037	-.026	.143	-.025	.143	-.352**	-.179
Willingness	-.154	.289*	-.097	-.209	-.132	-.018	-.142	.026	-.007	.013	.201	-.289*	-.160
Positive Affect	.111	.050	.042	-.110	-.195	.006	-.124	-.271*	-.202	-.056	.153	-.221	-.148
Negative Affect	-.219	-.032	-.103	-.065	-.021	-.093	.091	.079	.245	.200	.239	-.039	.119
After Discussion													
AD Knowledge	.077	.092	.109	-.080	-.019	.044	-.128	-.061	.025	-.214	-.047	-.260	.171
Attitudes	.161	.167	.185	-.135	-.051	.158	.095	.017	-.194	-.041	-.158	-.349**	-.315*
Willingness	-.114	.350**	-.067	-.284*	-.108	-.027	-.169	.084	-.103	-.045	.028	-.143	-.132
Positive Affect	.144	.079	.030	-.108	-.149	.040	-.197	-.282*	-.208	-.047	.092	-.259	-.070
Negative Affect	-.149	-.029	-.028	-.089	-.040	-.082	.162	.135	.229	.129	.095	.072	.285*

Note. Gen = Gender; Grade = Child's grade in school; AD# = Number of people the child knows with AD; Educ = Education; Mar = Marital status; ADpar = Parent or parent-in-law with AD; ADnon = Non-parent or parent-inlaw with AD; Lived = Lived with someone with AD; ADJob = Work or volunteer experience with people with AD; ADKS = parent score on the ADKS. Asterisks indicate significance level.

* $p < .05$; ** $p < .001$.

Table 7

Correlations between child and parent demographics and parent outcomes

	Children				Parents								
	Age	Gen	Grade	AD#	Age	Gen	Educ	Mar	ADpar	ADnonLived	ADJob	ADKS	
Baseline													
ADKS	-.062	-.168	-.133	.154	.005	-.062	.096	.002	.183	.027	.032	.214	---
AD Knowledge	-.249	.002	-.152	.116	-.003	-.306*	.034	.145	.116	.071	.087	-.030	.436**
Attitudes	.251	-.004	.133	-.010	-.162	.206	.057	.029	.071	.148	-.050	.472**	.328*
Willingness	.160	-.113	.174	-.402**	.102	-.034	-.215	.211	-.050	-.308*	-.150	.146	-.063
Positive Affect	.166	-.186	.182	-.015	.076	-.276*	-.059	-.177	-.080	.056	-.057	.110	.183
Negative Affect	-.089	.059	-.067	.138	.212	-.024	-.084	-.047	.034	.030	-.081	-.015	.114
Self-competence	.346*	-.186	.223	.209	.074	.032	.014	-.037	.207	.207	-.081	.296*	.082
After Reading													
Attitudes	.282*	-.043	.211	.018	-.155	.182	-.009	-.039	.100	.030	.140	.449**	.425**
Willingness	.277*	-.222	.250	-.457**	.134	.033	-.162	.175	-.054	-.325*	-.182	.169	.018
Positive Affect	.114	-.172	.184	.000	-.016	-.254	-.173	-.132	-.115	.017	.002	.098	.107
Negative Affect	-.041	.145	.040	.102	.284*	-.242	-.022	-.075	.055	-.060	-.091	.079	.138
Self-competence	.368**	-.176	.200	.065	-.063	.150	-.012	-.031	.041	.192	.024	.250	.026
After Discussion													
AD Knowledge	.086	.195	.053	.079	-.017	.419**	.042	-.038	-.243	-.157	.156	-.018	-.029
Attitudes	.283*	.005	.217	-.093	-.155	.219	-.127	-.016	-.024	-.032	.132	.407**	.374**
Willingness	.207	-.154	.202	-.426**	.079	.008	-.203	.167	-.071	-.307*	-.161	.205	.071
Positive Affect	.183	-.185	.290*	.039	-.018	-.284*	-.133	-.100	-.121	.079	-.011	.125	.099
Negative Affect	-.203	.107	-.148	.104	.208	-.223	.054	-.126	.104	.054	-.089	-.137	-.025
Self-competence	.544**	-.195	.369**	.061	.055	.212	-.086	-.004	.055	.007	.012	.345*	.094

Note. Gen = Gender; Grade = Child's grade in school; AD# = Number of people the child knows with AD; Educ = Education; Mar = Marital status; ADpar = Parent or parent-in-law with AD; ADnon = Non-grandparent with AD; Lived = Lived with someone with AD; ADJob = Work or volunteer experience with people with AD; ADKS = parent score on the ADKS. * $p < .05$; ** $p < .001$

References

- Abrams, M.A., Klass, P., Dreyer, B.P. (2009). Health literacy and children: Introduction. *Pediatrics*, 124, S262-264.
- Alton, S. & Lanning, F. (1979). Supportive therapy of books and the child. *Journal of the Association for the Study of Perception*, 14, 22-25.
- Alzheimer's Association. (2011). Parent's guide: helping children and teens understand Alzheimer's disease. http://www.alz.org/national/documents/brochure_childrenteens.pdf. Accessed June 1, 2012.
- Alzheimer's Association. (2013). Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 9(2).
- Alzheimer's Association. (2013). *Kids & Teens*. Retrieved from http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp
- Alzheimer's Disease Education and Referral Center. (2009). Helping children understand Alzheimer's Disease. <http://www.nia.nih.gov/alzheimers>
- Aram, D., Fine, Y., Ziv, M. (2013). Enhancing parent-child shared book reading interactions: Promoting references to the book's plot and socio-cognitive themes. *Early Childhood Research Quarterly*, 28, 111-122.
- Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice Hall.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NY: Prentice Hall.
- Bandura, A. (2001). Social cognitive theory of mass communication. *Mediapsychology*, 3, 265-299.

- Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior*, 31(2), 143-164.
- Bauer, C.J. (1985). Books can break attitudinal barriers toward the handicapped. *The School Counselor*, 32, 302-306.
- Bell, S.K., & Morgan, S.B. (2000). Children's attitudes and behavioral intentions toward a peer presented as obese: Does a medical explanation for the obesity make a difference? *Journal of Pediatric Psychology*, 25, 137-145.
- Berns CF. Bibliotherapy: Using books to help bereaved children. *OMEGA*. 2004; 48(4):321-336.
- Betz, C.L., Ruccione, K., Meeske, K., Smith, K., Chang, N. (2008) Health literacy: A pediatric nursing concern. *Pediatric Nursing*, 34(3), 231-239.
- Bibace, R. & Walsh, M.E. (1980). Development of children's concepts of illness. *Pediatrics*, 66, 912-917.
- Blendon, R.J., Benson, J.M., McCarthy, E., Wikler, K.J., Weldon, J., Baumgart, M., & Kallmyer, B.A. (2012). The impact of experience with a family member with Alzheimer's disease on views about the disease across five countries. *International Journal of Alzheimer's Disease*, 903645. doi:10.1155/2012/903645
- Blewitt, P., Rump, K., Shealy, S., & Cook, S. (2009). Shared book reading: When and how questions affect young children's word learning. *Journal of Educational Psychology*, 101, 294-304.
- Bonner, B. & Everett, F. (1982). Influence of client preparation and therapist prognostic expectations on children's attitudes and expectations of psychotherapy. *Journal of Clinical Child Psychology*, 11, 202-208.

- Borzekowski, D.L.G. (2009). Considering children and health literacy: A theoretical approach. *Pediatrics, 124*, S282-288.
- Bussey, K., & Perry, K. B. (1976). Sharing reinforcement contingencies with a model: A social-learning analysis of similarity effects in imitation research. *Journal of Personality and Social Psychology, 34*(6), 1168-1176.
- Byrne, E. & Nitzke, S. (2002). Preschool children's acceptance of a novel vegetable following exposure to messages in a storybook. *Journal of Nutrition Education and Behavior, 34*, 211-214.
- Carpenter, B.D., Balsis, S., Otilingam, P.G., Hanson, P.K., & Gatz, M. (2009). The Alzheimer's disease knowledge scale: Development and psychometric properties. *The Gerontologist, 49*, 236-247.
- Celdrán, M., Triadó, C., & Villar, F. (2011). "My grandparent has dementia": How adolescents perceive their relationships with grandparents with a cognitive impairment. *Journal of Applied Gerontology, 30*, 332-352.
- Cohen, L.J. (1987). Bibliotherapy: Using literature to help children deal with difficult problems. *Journal of Psychosocial Nursing and Mental Health Services, 25*, 20-24.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Hillsdale, N.J.: L. Erlbaum Associates.
- Coleman, D.J. & Kaplan, M.S. (1990). Effects of pretherapy videotape preparation on child therapy outcomes. *Professional Psychology: Research and Practice, 2*, 199-203.
- Creasey, G.L. & Jarvis, P.A. (1989). Grandparents with Alzheimer's disease: Effects of parental burden on grandchildren. *Family Therapy, 16*, 79-85.

- Creasey, G.L., Myers, B.J., Epperson, M.J., & Taylor, J. (1989). Grandchildren of grandparents with Alzheimer's disease: Perceptions of grandparent, family environment, and the elderly. *Merrill-Palmer Quarterly*, 35(2), 227-237.
- Cumming, G., & Finch, S. (2005). Inference by eye: Confidence intervals and how to read pictures of data. *American Psychologist*, 60, 170-180.
- Deal, T. B., Jenkins, J.M., Deal, L.O., & Byra, A. (2010). The impact of professional development to infuse health and reading in elementary schools. *American Journal of Health Education*, 41, 155-166.
- Dyches, T. T., & Prater, M. A. (2005). Characterization of developmental disability in children's fiction. *Education and Training in Developmental Disabilities*, 40(3), 202-216.
- Dyches, T.T., Prater, M.A., Cramer, S.F. (2001). Characterization of mental retardation and autism in children's books. *Education and Training in Mental Retardation and Developmental Disabilities*, 36, 230-243.
- Eagly, A.H., (2009). The his and hers of prosocial behavior: An examination of the social psychology of gender. *American Psychologist*, 64, 644-658
- Ebesutani, C., Regan, J., Smith, A., Reise, S., Higa-McMillan, C., & Chorpita, B.F. (2012). The 10-Item Positive and Negative Affect Schedule for Children, Child and Parent Shortened Versions: Application of Item Response Theory for More Efficient Assessment. *J Psychopathol Behav Assess*, 34, 191–203.
- Eisenberg, N., Miller, P.A., Shell, R., McNalley, S., & Shea, C. (1991). Prosocial development in adolescence: A longitudinal study. *Developmental Psychology*, 27, 849-857.
- Faul, F. Erdfelder, E., Lang, A., & Buchner, A. (2009). G*Power. [Software]

- Faust, J., Olson, R., & Rodriguez, H. (1991). Same-day surgery preparation: Reduction of pediatric patient arousal and distress through participant modeling. *Journal of Consulting and Clinical Psychology, 59*, 475-478.
- Femia, E.E., Zarit, S.H., Blair, C., Jarrott, S.E., Bruno, K. (2008). Intergenerational preschool experiences and the young child: Potential benefits to development. *Early Childhood Research Quarterly 23*, 272-287.
- Franti A. (2002). *Grandma's Cobwebs*. Clifton Park, NY: Dagney Publishing.
- Fruhauf, C. A., & Orel, N. A. (2008). Developmental issues of grandchildren who provide care to grandparents. *International Journal of Aging and Human Development, 67*(3), 209-230.
- Fuh, J. L., Wang, S. J., & Juang, K. D. (2005). Understanding of senile dementia by children and adolescents: Why grandma can't remember me? *Acta Neurologica Taiwanica, 14*, 138-142.
- Ganea, P.A., Ma, L., & DeLoache, J.S. (2011). Young children's learning and transfer of biological information from picture books to real animals. *Child Development, 82*, 1421-1433.
- Ganea, P.A., Pickard, M.B., & DeLoache, J.S. (2008). Transfer between picture books and the real world by very young children. *Journal of Cognition and Development, 9*, 46-66.
- Glang, A., Noell, J., Ary, D., Swartz, L. (2005). Using interactive multimedia to teach pedestrian safety: An exploratory study. *American Journal of Health Behavior, 29*, 435-442.
- Goodnow, J. J., & Lawrence, J. A. (2001). Work contributions to the family: Developing a conceptual and research framework. In A.J. Fuligni (Ed.), *Family obligation and*

- assistance during adolescence: Contextual variations and developmental implications* (pp. 5-22). San Francisco, CA: Jossey-Bass.
- Gosselin, K. (2002). *Allie learns about Alzheimer's disease: A Family Story about Love, Patience, and Acceptance*. Plainview, NY: JayJo Books, LLC.
- Greenhough, P. & Hughes, M. (1998). Parents' and teachers' interventions in children's reading. *British Educational Research Journal*, 24, 383-398.
- Hamill, S.B. (2012). Caring for grandparents with Alzheimer's disease: Help for the "forgotten" generation. *Journal of Family Issues*, 33, 1195-1127.
- Home Box Office. (Producer). (2009). *The Alzheimer's project* [DVD]. Available from <http://www.hbo.com/alzheimers/>
- Howard, K. & Singleton, J.F. (2001). The forgotten generation: The impact a grandmother with Alzheimer's disease has on a granddaughter. *Activities, Adaptation, & Aging*, 25, 45-57.
- Hudson, M.E. & Test, D.W. (2011). Evaluating the evidence base of shared story reading to promote literacy for students with extensive support needs. *Research and Practice for Persons with Severe Disabilities*, 36, 34-45.
- Jarrott, S.E. & Bruno, K. (2007). Shared site intergenerational programs: A case study. *Journal of Applied Gerontology*, 26(3), 239-257.
- Justice, L.M., & Lankford, C. (2002). Preschool children's visual attention to print during storybook reading: Pilot findings. *Communication Disorders Quarterly*, 24, 11-21.
- Kalish, C. (1996). Causes and symptoms in preschoolers' conceptions of illness. *Child Development*, 67, 1647-1670.
- Kalish, C. W. (1998). Young children's predictions of illness: Failure to recognize probabilistic causation. *Developmental Psychology*, 34, 1046-1058.

- LaBounty, J., Wellman, H.M., Olson, S., Lagattuta, K., & Liu, D. (2008). Mothers' and Fathers' use of internal state talk with their young children. *Social Development, 17*, 757-775.
- La Fontaine, J., & Oyeboode, J. R. (2013). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. *Ageing and Society, not sure about the volume*, 1-30.
- Li, H.C.W., Lopez, V., & Lee, T.L.I. (2007). Effects of preoperative therapeutic play on outcomes of school-age children undergoing day surgery. *Research in Nursing and Health, 30*, 320-332.
- Lundquist, T.S. & Ready, R., E. (2008). Young adult attitudes about Alzheimer's disease. *American Journal of Alzheimer's disease and Other dementias, 23*, 267-273.
- Mace, N. L., & Rabins, P. V. (2001). *The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Late*. New York, NY: Warner Books.
- Magnuson, S. (1999). Strategies to help students whose grandparents have Alzheimer's disease. *Professional School Counseling, 2*(4), 327-333.
- Malcom, N. L. (2010-2011). Images of heaven and the spiritual afterlife: Qualitative analysis of children's storybooks about death, dying, grief, and bereavement. *OMEGA, 62*(1), 51-76.
- Manthorpe, J. (2005). A child's eye view: Dementia in children's literature. *British Journal of Social Work, 35*, 305-320.
- Manworren, R. C. B., & Woodring, B. (1998). Evaluating children's literature as a source for patient education. *Pediatric Nursing, 24*(6), 548-553.

- Marriott, A., Donaldson, C., Tarrier, N., & Burns, A. (2000). Effectiveness of cognitive-behavioural family intervention in reducing the burden of care in carers of patients with Alzheimer's disease. *British Journal of Psychiatry*, 176, 557-562.
- McIntosh, C., Stephens, C., & Lyons, A. (2013). "Remember the bubbles hurt you when you cook in the pan": Young children's views of illness causality. *Psychology, Health & Medicine*, 18, 21-29.
- McKeachie, W.J., & Svinicki, M. (Eds.) (2006). *Teaching tips: Strategies, research, and theory for college and university teachers*. Boston: Houghton Mifflin Company.
- National Alliance for Caregiving & AARP. (2009). *Caregiving in the U.S. 2009*. Retrieved from <http://www.caregiving.org/research/caregiving-research/general-caregiving>
- Nichols, K. R., Fam, D., Cook, C., Pearce, M., Elliot, G., Baago, S., Rockwood, K., & Chow, T. W. (2013). When dementia is in the house: Needs assessment survey for young caregivers. *The Canadian Journal of Neurological Sciences*, 40, 21-28.
- O'Connor, M.L. & McFadden, S.H. (2010). Development and Psychometric Validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*, 2010, 1-10.
- Orel, N.A. & Dupuy, P. (2002). Grandchildren as auxiliary caregivers for grandparents with cognitive and/or physical limitations: Coping strategies and ramifications. *Child Study Journal*, 32(4), 193-213.
- Ornachi, V., Brockmeier, J., & Gavazzi, I. G. The role of language games in children's understanding of mental states: A training story. *Journal of Cognition and Development*, 12, 239-259.
- Pardeck J, & Pardeck J, (Eds.) (1993). *Bibliotherapy: a clinical approach for helping children*. Langhorne, PA: Gordon and Breach Science Publishers.

- Poling, D. A., & Hupp, J. M. (2008). Death sentences: A content analysis of children's death literature. *Journal of Genetic Psychology, 169*(2), 165-176.
- Pollack P., & Belviso M. (2009). *Grandpa Has Changed*. Hauppauge, NY: Barron's Educational Series, Inc.
- Praeter, M. A., Dyches, T. T., & Johnstun, M. (2006). Teaching students about learning disabilities through children's literature. *Intervention in School and Clinic, 42*(1), 14-24.
- Rawlinson, S. C., & Short, J. A. (2007). The representation of anaesthesia in children's literature. *Anesthesia, 62*(10), 1033-1038.
- Robinson, L. D., Calmes, D. P., & Bazargan, M. (2008). The impact of literacy engagement on asthma-related outcomes among underserved children. *Journal of the National Medical Association, 100*, 892-896.
- Rowe, G., & Jacobs, K. (2002). Efficacy of body mechanics education on posture while computing in middle school children. *Work, 18*, 295-303.
- Sakai, E.Y., Carpenter, B.D., & Rieger, R.E. (2012). "What's wrong with grandma?": Depictions of Alzheimer's disease in children's storybooks. *American Journal of Alzheimer's Disease & Other Dementias, 27*, 584-591.
- Sakai, E.Y., Carpenter, B.D., & Rieger, R.E. Untitled. Manuscript in Preparation.
- Sanders, L. M., Shaw, J. S., Guez, G., Baur, C., & Rudd, R. (2009). Health literacy and child health promotion: Implications for research, clinical care, and public policy. *Pediatrics, 124*, S306-S314.
- Schnurbush B. (2006). *Striped Shirts and Flower Pants: A Story about Alzheimer's Disease for Young Children*. Washington, DC: Magination Press.

- Seibert, D., & Drolet, J.C. (1993). Death themes in literature for children ages 3-8. *Journal of School Health*, 63, 89-93.
- Semel, E., Wiig, E.H., & Secord, W.A. (2003). *Clinical Evaluation of Language Fundamentals-Fourth Edition*.
- Sharma, M., & Romas, J.A. (2012). *Theoretical foundations of health education and health promotion* (2nd ed.). Burlington, MA: Jones & Bartlett Learning.
- Shepherd, T.R. & Koberstien, J. (1989). Books, puppets, and sharing: Teaching preschool children to share. *Psychology in the Schools*, 26, 311-316.
- Simons-Morton, B. G., McLeroy, K. R., Wendel, M. L. (2012). *Behavior theory in health promotion practice and research*. Burlington, MA: Jones & Bartlett Learning.
- Svanberg, E., Stott, J., & Spector, A. (2010). “Just helping”: Children living with a parent with young onset dementia. *Aging and Mental Health*, 14, 740-751.
- Symons, D.K., Peterson, C.C., Slaughter, V., Roche, J., Doyle, E. (2005). Theory of mind and mental state discourse during book reading and story-telling tasks. *British Journal of Developmental Psychology*, 23, 81-102.
- Thornton, C.M. & Piacquadio, D.J. (1996). Promoting sun awareness: Evaluation of an educational children’s book. *Pediatrics*, 98, 52-55.
- Turner, J. C. (2006). Representations of illness, injury, and health in children’s picture books. *Children’s Health Care*, 25(2), 179-189.
- U.S. Department of Health and Human Services. (2000). *Healthy People 2010*. Understanding and Improving Health and Objectives for Improving Health (2nd ed., Vol.1) Washington, DC: U.S. Government Printing Office.

- Valle, R., Yamada, A., Matiella, A. C. (2006). Fotonovelas: A health literacy tool for educating Latino older adults about dementia. *Clinical Gerontologist, 30*(1), 71-88.
- Watson, D., Clark, L.A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology, 54*, 1063-1070.
- Werner, P. (2001). Correlates of family caregivers' knowledge about Alzheimer's disease. *International Journal of Geriatric Psychiatry, 16*, 32-38.
- Werner, P. (2003). Knowledge about symptoms of Alzheimer's disease: Correlates and relationship to help-seeking behavior. *International Journal of Geriatric Psychiatry, 18*, 1029-1036.
- Whitehurst, G.J., Falco, F.L., Fischel, J.E., DeBaryshe, B.D., Valdez-Menchaca, M.C., & Caulfield, M. (1988). *Developmental Psychology, 24*, 552-559.
- Whitehurst, G.J., Arnold, D.S., Epstein, J.N., Angell, A. L., Smith, M., & Fischel, J.E. (1994). A picture book reading intervention in day care and home for children from low income families. *Developmental Psychology, 30*, 679-689.
- Wolf, M.S., Wilson, E.A.H., Rapp, D.N., Waite, K.R., Bocchini, M.V., Davis, T.C., & Rudd, R.E. (2009). Literacy and learning in health care. *Pediatrics, 124*, S275-S281

Appendix I: Discussion Questions for Parents

- Explain the disease
 - What kind of changes do Allie and her mother notice in Grandma? What kinds of “strange” behaviors does Grandma have?
 - (Answers: She is forgetful, got lost in the grocery store, Grandma was pacing in her driveway, talking to herself and wringing her hands, suspicious of the neighbor boy, anger)
 - What would you do if you noticed these changes in your own grandparent?
 - How do you think you would feel if you noticed these changes in your grandparent?
 - How does Allie’s mother know that Grandma had Alzheimer’s disease?
 - (Answers: She take Grandma to the doctor, The doctor runs a number of tests)
- Discuss grandparent’s feelings
 - How do you think Allie’s grandmother feels about her Alzheimer’s disease?
 - What are some things that Allie could do to make her grandmother feel better?
- Parents
 - How does Allie’s mother respond to the signs that Grandma has Alzheimer’s disease?
 - (Answers: Allie’s mom is gentle with Grandma—leading her gently into the house, Mom is patient)
 - What kinds of stress might Allie’s mother be experiencing?
- Child’s experience after AD diagnosis
 - How does Allie’s life change when her grandmother is diagnosed with Alzheimer’s?
 - How would you feel if your life changed in the same way that Allie’s did?
 - How did Allie act/ behave when she learned that her grandmother had Alzheimer’s disease?
 - How might you behave (what would you do) if one of your grandparents had Alzheimer’s disease?
 - What would you tell your friends if one of your grandparents had Alzheimer’s disease?
- Help child identify their feelings
 - How did Allie feel when she learned that her grandmother had Alzheimer’s disease?
 - How would you feel if one of your grandparents had Alzheimer’s disease?
- Coping with Alzheimer’s disease
 - What kinds of activities do Allie and her family do to cope with her grandmother’s Alzheimer’s disease in this book (What do they do to feel better)?
 - If one of your grandparents had Alzheimer’s disease, what would you do to cope with it?

Appendix II: Alzheimer’s disease Knowledge Scale for Children

I will read some things about Alzheimer’s disease. Tell me whether you think they are True or False. If you aren’t sure of the right answer, make your best guess.

True	False	1.	People with Alzheimer’s disease have pain in their hands and fingers.
True	False	2.	People can catch Alzheimer’s disease from someone who has it.
True	False	3.	People with Alzheimer’s disease cannot help the way they act.
True	False	4.	Having Alzheimer’s disease is the same thing as becoming senile.
True	False	5.	One person with Alzheimer’s disease may have different problems than another person with Alzheimer’s disease.
True	False	6.	People with Alzheimer’s disease may accidentally do dangerous things.
True	False	7.	There is a cure for Alzheimer’s disease.
True	False	8.	Children should not spend time with people with Alzheimer’s disease.
True	False	9.	Sometimes people with Alzheimer’s disease get lost.
True	False	10.	People with Alzheimer’s disease have problems with memory.
True	False	11.	It is hard for doctors to know if someone has Alzheimer’s disease.
True	False	12.	People with Alzheimer’s disease cannot hear as well as other people who are the same age.
True	False	13.	Doctors only need to do one test to know whether someone has Alzheimer’s disease.
True	False	14.	People with Alzheimer’s disease have trouble controlling how they feel.
True	False	15.	People can have Alzheimer’s disease but still be physically healthy.
True	False	16.	People who take care of someone with Alzheimer’s disease need a break sometimes.
True	False	17.	Young children can get Alzheimer’s disease.
True	False	18.	People with Alzheimer’s disease sometimes may not trust other people.

True	False	19.	Medicine can help people with Alzheimer's disease.
True	False	20.	People with Alzheimer's are not able to do things that they enjoy.

Appendix III: Alzheimer's disease Attitudes Scale for Children

Think about how you feel about someone who has Alzheimer's disease. Tell me how much you agree with the following statements.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

1	I feel uncomfortable around people with Alzheimer's disease	1	2	3	4
2	I would rather spend time with my friends than a family member with Alzheimer's disease	1	2	3	4
3	I'm confident of myself when I'm around people with Alzheimer's disease	1	2	3	4
4	I am scared of people with Alzheimer's disease	1	2	3	4
5	People with Alzheimer's disease can enjoy life	1	2	3	4
6	It can be fun to spend time with people with Alzheimer's disease	1	2	3	4
7	I feel bad for people with Alzheimer's disease	1	2	3	4
8	People with Alzheimer's disease cannot do things that they want to do	1	2	3	4
9	People with Alzheimer's disease do not know when other people are nice to them	1	2	3	4
10	If someone with Alzheimer's disease needed help with something, I would help them	1	2	3	4

Appendix IV: Alzheimer's disease Willingness Scale for Children

If someone in your family had Alzheimer's disease, like Grandma, how much would you want to...

1 2 3 4
 Not at all A little bit Quite a bit A lot

Learn more about Alzheimer's disease	1	2	3	4
Spend more time with the person who has Alzheimer's disease	1	2	3	4
Do more chores around the house to help your parents	1	2	3	4
Spend less time with your friends so you can be with the person with Alzheimer's disease	1	2	3	4
Help take care of the person with Alzheimer's disease	1	2	3	4
Talk to the person with Alzheimer's disease about his/her life	1	2	3	4
Look through photo albums with the person with Alzheimer's disease	1	2	3	4
Find fun things to do with the person with Alzheimer's disease	1	2	3	4
Give the person with Alzheimer's disease more hugs or kisses	1	2	3	4

Appendix V: Alzheimer's disease Willingness Scale for Parents

If you had someone in your family with Alzheimer's disease, like Grandma, how much would you...

1
2
3
4
Not at all
A little bit
Quite a bit
A lot

Spend less time with your friends in order to spend more time with the person who has Alzheimer's disease	1	2	3	4
Learn more about Alzheimer's symptoms	1	2	3	4
Spend more time with the person who has Alzheimer's disease	1	2	3	4
Ask your child to do more chores around the house	1	2	3	4
Help take care of the person with Alzheimer's disease	1	2	3	4
Talk to the person with Alzheimer's disease about his/her life	1	2	3	4
Look through photo albums with the person with Alzheimer's disease	1	2	3	4
Find activities to do with the person with Alzheimer's disease	1	2	3	4
Give the person with Alzheimer's disease more hugs or kisses	1	2	3	4

Appendix VI: Alzheimer's disease Self-competence Scale for Parents

Please rate how competent you feel about discussing Alzheimer's disease or helping your child's understanding of Alzheimer's disease.

1	2	3	4
Not at all Competent	Somewhat Competent	Mostly Competent	Very Competent

	1	2	3	4
Rate your OVERALL ability to discuss Alzheimer's disease with your child	1	2	3	4
Discussing Alzheimer's symptoms	1	2	3	4
Discussing how Alzheimer's disease is diagnosed	1	2	3	4
Discussing Alzheimer's treatments	1	2	3	4
Discussing the changes that might occur in the child's life as a result of a loved one's Alzheimer's diagnosis	1	2	3	4
Discussing the feelings that someone with Alzheimer's may have	1	2	3	4
Discussing the stresses that you, as a parent, may experience when providing care for someone with Alzheimer's disease	1	2	3	4
Discussing the child's emotions/feelings about the person's Alzheimer's diagnosis	1	2	3	4
Discussing what the child might say to his/her friends about the person's Alzheimer's diagnosis	1	2	3	4
Discussing how the child might behave with someone with Alzheimer's disease	1	2	3	4
Showing the child how to talk and act with someone with Alzheimer's disease	1	2	3	4
Actively helping the child talk and act with someone with Alzheimer's disease	1	2	3	4
Discussing how a child could cope/deal with a loved one's Alzheimer's diagnosis	1	2	3	4
Providing support to child (e.g., showing concern toward the child)	1	2	3	4

ERIN Y. SAKAI
Washington University in St. Louis
Department of Psychology, Campus Box 1125
St. Louis, MO 63130

EDUCATION

- Washington University in St. Louis, St. Louis, MO** 2008-present
Fifth-Year in Psychology Ph.D. Program (Clinical)
Major Advisor: Brian D. Carpenter, Ph.D.
Dissertation: “Effect of Reading and Discussing a Storybook about Alzheimer’s Disease on Children and Parents”
Committee: Brian D. Carpenter, Ph.D. (chair)
Proposed: May 2012
Defended: April 25, 2014
- Washington University in St. Louis, St. Louis, MO** 2009
Master of Arts (A.M.) in Psychology
Major Advisor: Brian D. Carpenter, Ph.D.
Master’s Project: “Power During the Disclosure of a Dementia Diagnosis”
Committee: Brian D. Carpenter, Ph.D. (chair)
- Harvard Extension School, Cambridge, MA** Spring 2007
- Wellesley College, Wellesley, MA** 2006
Bachelor of Arts (B.A.) in Neuroscience; Minor: English

ACADEMIC HONORS AND AWARDS

- Dissertation Fellowship**, Washington University in St. Louis 2012-2013
- Graduate School of Arts and Sciences Travel Award**, Washington University in St. Louis 2008-2012
- Graduate School of Arts and Sciences Teaching Assistantship**, Washington University in St. Louis 2010-2012
- Behavioral and Social Sciences Section Travel Award**, Gerontological Society of America 2009
- Aging and Development Training Grant**, Washington University in St. Louis 2009-2010
- Graduate School of Arts and Sciences University Fellowship**, Washington University in St. Louis 2008-2009

CLINICAL TRAINING AND ACTIVITIES

Psychology Intern

08/13-

present

VA Palo Alto Healthcare System, Palo Alto, CA

Rotations: Hospice and Palliative Care

- Provide inpatient psychotherapy and psychological assessment for medically-ill patients at the end-of-life and their families; Coordinate care with interdisciplinary team and attend team meetings

Rotation: Behavioral Medicine

- Provide outpatient psychotherapy for individuals with pain, sleep, health-related anxiety, and medical compliance issues
- Conduct transplant evaluations
- Smoking Cessation clinic: Provide outpatient individual psychotherapy for smoking cessation and lead psychoeducation group
- MOVETIME clinic: Evaluate and provide interventions for individuals interested in weight loss or bariatric surgery

Rotation: Home-based Primary Care

- Provide psychotherapy and psychological assessment for medically-ill patients in-home; Coordinate care with interdisciplinary team

Rotation: Inpatient Psychiatry

- Provide individual and group psychotherapy to patients with psychiatric disorders; Participate in treatment team meetings and coordinate care with interdisciplinary team

Rotation: Family Therapy Program

- Provide psychotherapy and psychological assessment to couples; Provide feedback as part of live supervision team

Student Therapist

09/09-06/13

Psychological Service Center, St. Louis, MO

- Provide outpatient psychotherapy and psychological assessment for individuals and couples

Neuropsychology Assistant

06/11-06/13

Psychological Service Center, St. Louis, MO

- Develop batteries, conduct neuropsychological interviews and assessments, write neuropsychological reports and provide feedback to clients.

Psychology Practicum Student

St. Louis Veterans Administration, St. Louis, MO

12/11-08/12

- Provide inpatient psychotherapy and cognitive assessment as part of an inpatient psychology service to geriatric, hospice/palliative care, and stroke/rehabilitation units

- Coordinated patient care and discharge planning with interdisciplinary team and attended team meetings.
- Co-facilitate weekly “Healthy Minds, Healthy Lifestyles” stress and behavior management group for individuals in the cardiopulmonary rehabilitation program.

Neuropsychological Assistant

Charles and Joanne Knight Alzheimer’s Disease Research Center, 06/11-08/12
St. Louis, MO

- Administer and score cognitive assessments for healthy and very mildly cognitively impaired participants in the Memory and Aging Project

Psychology Practicum Student

Siteman Cancer Center, St. Louis, MO 05/11-08/11

- Provide psychotherapy with cancer patients, family members, or couples in both outpatient and inpatient settings

Psychotherapy Practicum Student

SSM St. Mary’s Rehabilitation Hospital, St. Louis, MO 09/10-05/11

- Conduct assessment and therapy in an inpatient medical rehabilitation hospital for patients with stroke, traumatic brain injury, amputation, or medical illness
- Co-lead weekly group therapy sessions focusing on adjustment to illness or injury.
- Attend weekly team conferences and present individual cases; coordinate care with interdisciplinary team

CLINICAL SUPERVISION EXPERIENCE

Graduate Student Psychotherapy Peer Supervisor

Washington University, St. Louis, MO 2012-2013

- Provide supervision to a graduate student for clinical cases, including discussion of case conceptualization, intervention, and basic therapy skills.

Graduate Student Assessment Peer Supervisor

Washington University, St. Louis, MO 2010-2011

- Provide supervision and feedback to graduate students on clinical assessments and neuropsychological testing

RESEARCH EXPERIENCE

Graduate Research Assistant, Clinical Geropsychology Lab

Washington University, St. Louis, MO 08/08-05/14

- Alzheimer’s disease Children’s Storybook study

- Developed a study examining the portrayal of Alzheimer’s disease in children’s picture books. Created a coding scheme for books and trained research assistants to code books.
- Utilized a quasi-experimental design to examine the effect of reading and discussing a storybook about Alzheimer’s disease on young children (ages 7 and 8) and their parents on knowledge, attitudes, and willingness to interact with individuals with Alzheimer’s disease. Developed questionnaires addressing knowledge, attitudes, and willingness to interact with people with Alzheimer’s disease for young children.
- Geropsychology Survey study
 - Examined the outcomes (e.g., career paths) of individuals trained in Geropsychology to identify training opportunities that promote leadership in Geropsychology. Contributed to survey development, participant recruitment, and data collection. Will be involved in analysis and manuscript writing.
- Dementia Diagnostic Feedback study
 - Examined the linguistic features of dementia diagnostic feedback sessions. Transcribed feedback sessions and analyzed the transcriptions using the Linguistic Inquiry and Word Count (LIWC) text analysis program.
- Social Support study
 - Examined the exchange of social support between older, heterosexual married couples. More specifically, evaluated three different types of consensus on two subscales of support, emotional and instrumental support. Presented data at national conference.
- Dementia Diagnostic Feedback study
 - Examined the linguistic features of dementia diagnostic feedback sessions. Transcribed feedback sessions and analyzed the transcriptions using the Linguistic Inquiry and Word Count (LIWC) text analysis program. Primary author of a published manuscript and presented data at a national conference.
- Wachovia study
 - Examined the extent to which older adults discuss finances and financial matters with their families. Analyzed data from a national telephone survey. Presented data at a national conference. Manuscript is in progress.

Clinical Research Assistant, Behavioral Neurology Unit

Beth Israel Deaconess Medical Center, Boston, MA

08/06-06/08

Principal Investigator: Michael P. Alexander, M.D.

- Screened and recruited individuals for a cerebellum lesion study. Tested patients and controls with neuropsychological assessments and computer-based attention measures. Traced brain lesions using MRIcro

Research Assistant

Hawaii State Hospital, Kaneohe, HI

06/05-08/05

Principal Investigator: Daryl Fujii, Ph.D.

PEER-REVIEWED PUBLICATIONS

Sakai, E.Y., Carpenter, B.D., & Rieger, R. E. (2012). "What's Wrong with Grandma?": Depictions of Alzheimer's Disease in Children's Storybooks. *American Journal of Alzheimer's disease and Associated Disorders*.

Sakai, E.Y. & Carpenter, B.D. (2011). Linguistic Features of Power Dynamics in Triadic Dementia Diagnostic Conversations. *Patient Education and Counseling*, 85, 295-8.

BOOK CHAPTERS

Fujii, D. & **Sakai, E.** (2007). Cocaine psychosis. In D. Fujii & I. Ahmed (Eds.), The spectrum of psychotic disorders: Neurobiology, etiology & pathogenesis. Cambridge, United Kingdom

MANUSCRIPTS IN PREPARATION

Sakai, E.Y. & Carpenter, B.D. (In Preparation). The portrayal of Alzheimer's Disease in Children's Storybooks.

POSTER PRESENTATIONS AT NATIONAL CONFERENCES

Sakai, E.Y., Carpenter, B.D., & Rieger, R.E. (Accepted). Depiction of Alzheimer's Disease Features in Children's Storybooks. 122nd Meeting of the American Psychological Association. Washington, D.C.

Sakai, E.Y., Carpenter, B.D., & Rieger, R.E. (November, 2012). Depiction of Alzheimer's Disease Features in Children's Storybooks. 64th Meeting of the Gerontological Society of America. San Diego, CA.

Zaleta, A.K., Carpenter, B.D., **Sakai, E.Y.** (November, 2011). The 'A' Word: Use of 'Alzheimer's Disease' During Diagnostic Conversations 63rd Annual Scientific Meeting of the Gerontological Society of America. Boston, MA.

Sakai, E.Y. & Carpenter, B.D. (February, 2011). Varieties of Spousal Agreement about Emotional and Instrumental support. Washington University in St. Louis 16th Annual Graduate Student Research Symposium. St. Louis, MO.

Sakai, E.Y. & Carpenter, B.D. (November, 2010). Varieties of Spousal Agreement about Emotional and Instrumental support. 62nd Annual Scientific Meeting of the Gerontological Society of America. New Orleans, LA.

Carpenter B.D., **Sakai E.Y.**, Zoller S.M. (November, 2009). What Economic Crisis? Late-life Family Reluctance to Discuss Finances. 61st Annual Scientific Meeting of the Gerontological Society of America. Atlanta, GA.

Zaleta A.K., Carpenter B.D., **Sakai E.Y.** (November, 2008). Delivering a Dementia Diagnosis: Do Patients and Companions Get the Message? 60th Annual Scientific Meeting of the Gerontological Society of America. National Harbor, MD.

Schweizer T.A., Alexander M.P., Gillingham S., **Sakai E.**, Cusimano M., Stuss D. (November, 2008). Poor Initiation and Low Switch Rate on a Verbal Fluency Task Following Right Cerebellar Lesions. 38th Annual Meeting of the Society for Neuroscience. Washington, DC.

SYMPOSIUM PRESENTATIONS AT NATIONAL CONFERENCES

Sakai, E.Y. (November, 2011). What's Happening to Grandma?: The Portrayal of Alzheimer's disease in Children's Books. 63rd Annual Scientific Meeting of the Gerontological Society of America. Boston, MA.

Sakai, E.Y. (November, 2009). Analysis of Key Linguistic Features in a Triadic Dementia Diagnostic Conversation. 61st Annual Scientific Meeting of the Gerontological Society of America. Atlanta, GA.

INVITED TALKS

Sakai, E.Y. & Carpenter, B.D. (October, 2011). What's Wrong with Grandma?: Depictions of Dementia in Children's Storybooks. Invited talk at Charles F. and Joanne Knight Alzheimer's Disease Research Center Research Seminar. Washington University Alzheimer's Disease Research Center.

INTERVIEWS WITH THE MEDIA

Span, P. (2012, October 5) Books to Teach Children about Alzheimer's. *The New York Times*. Retrieved from <http://newoldage.blogs.nytimes.com/2012/10/05/books-to-teach-children-about-alzheimers/?ref=health>

TEACHING EXPERIENCE

Lecturer, Introduction to Psychology

Summer 2012

Department of Psychology, Washington University, St. Louis, MO

- Developed course syllabus, content, quizzes, and exams
- Developed lectures for the course and presented them to students.

Graduate Teaching Assistant 2010-2012
Department of Psychology, Washington University, St. Louis, MO
 Courses: Social Psychology, Abnormal Psychology, Personality Psychology, Biological Psychology

MEMBERSHIP IN PROFESSIONAL ORGANIZATIONS

Gerontological Society of America 2005-present
 Association for Psychological Science, *Student Member* 2009-present
 American Psychological Association 2010-present
 Division 12/II, *Student Member* 2011-present

PROFESSIONAL ACTIVITIES

Ad Hoc Reviewer, *Western Journal of Nursing Research*
 Student Representative, *Mentoring Committee* 2011-present
 American Psychological Association, Division 12/II Clinical Geropsychology

SERVICE

Internship

Diversity and Multicultural Committee, Psychology Service 2013-present

Department

Clinical Studies Committee Student Representative, Dept of Psychology 2012-2013
Prospective Student Host and Interviewer, Department of Psychology 2009-2013
Co-Chair/President, Psychology Graduate Student Association 2010-2011
Peer Mentor, Psychology Graduate Student Association 2009-2010
Social Committee co-chair, Psychology Graduate Student Association 2009-2010
Undergraduate Psychology Mentor, Department of Psychology 2010

University

Psychology Student Representative, Washington University Graduate Council 2010-2011
Committee Member, Washington University Policies and Services Committee 2010-2011

Community

Group Co-facilitator, Aphasia Caregiver Support Group Barnes-Jewish Extended Care 2010-2011