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Grandma, Don't Forget How Much I Love You: A Teaching and Learning Resource Embedded in the Rich Jamaican Culture

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Book Review

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Abstract

Culture affects the personal meaning underlying the experience of chronic conditions, such as Alzheimer's Disease (AD). Health care providers must strive to accommodate the variations of these needs. There is also growing recognition that persons with AD are members of mutigenerational families and must be treated within context of the whole. Children and family picture books on AD have been published for a variety of cultures and ethnic groups to promote understanding and awareness. However, up until now, none of these books have focused on the people of Jamaica. The authors have combined their unique skills to fulfill the critical need for a culturally responsive story, embedded in the rich Jamaican culture. This book is not limited to persons living in Jamaica, but also persons of Jamaican heritage who are living in another country. This book also has potential as an important resource for the Caribbean population. Importantly, this story is theoretically grounded in empirical and clinical evidence for the care of persons with AD. This knowledge is translated into an age-appropriate story that is engaging and empowering to the child. The story uses a problem-solving approach to better understand behaviors associated with the disease and how to make the necessary adaptations. Amancia and Mother help to build upon Grandma's preserved abilities such as singing hymns, keeping her Bible close, and enjoying regional fruits and traditional family meals. Grandma is treated with respect and love. The story is intended to raise understanding and awareness as well as eliminate the negative stigma that may be associated with the disease. Author notes are included for parents and healthcare providers to assist them to enhance the learning experience for the child. Five hundred hardcopies of the book are being donated to public libraries and schools in Jamaica.

Keywords: Alzheimer's Disease; Dementia; Jamaica; Children; Family; Picture Book; Culture; Promote Understanding

Introduction

Persons with ADRD Living in Jamaica

In 2020, over 55 million people throughout the world were living with Alzheimer's disease and related dementias (ADRD) [1]. Dementia has the potential to effect persons of all races, cultures and ethnicities. Individual expression of culture and ethnicity, may influence the personal meaning underlying the experience of dementia and should be honored to accommodate the associated variations of needs [2]. However, some countries, such as Jamaica, have limited resources.

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In 2018, Eldemire-Shearer and colleagues [3] conducted the first national study in Jamaica and reported 5.9% of persons had dementia. This rate was identified as being comparable to regional and global estimates at the time [3]. More specifically, 61.8% of Jamaicans with dementia had "Alzheimer's pattern dementia" with 32.4% having vascular dementia [3]. In 2018, *The Gleaner* [4], a daily newspaper in Kingston, Jamaican; predicted by 2030 there could be as many as 31,000 people in Jamaica living with dementia.

In 2018 *Alzheimer's Jamaica*, a member of *Alzheimer's Disease* International, joined an international campaign to raise awareness and understanding of dementia and eliminate the negative stigma that is too often associated with this disease.

A foreshadowing of these concerns became apparent in 1999, with awareness of increased longevity in Caribbean persons 60 years and older [5]. This shift was attributed to: 1) a significant decline in mortality, 2) a decline in fertility rate, and 3) an increase in life expectancy. This was concurrently associated with an increase in chronic illness, such as ADRD. These findings emphasized the challenges and necessary support for Jamaican families caring for a person with ADRD [5]. The average life expectancy in Jamaica during 1999 was 70.9 years. By 2023, the average life expectancy increased to 74.88 years [6].

In 2021, Govia and colleagues [7] initiated a long-term care assessment for Jamaica's aging population. This was accompanied by a needs assessment for future sustainability. A key finding of these initial efforts identified women and children as the primary informal care providers of persons with dementia. There is a reluctance for some Jamaicans to share sensitive matters, such as this, outside of the family. Consequently, community education about ADRD is identified as an important need [8].

Geographic Distribution of Persons with a Jamaican Heritage

To fully address the need for education related to ADRD, it is also important to identify the prevalence of persons of Jamaican heritage who are living outside their country of origin. During 2019, approximately 4.5% persons of Caribbean decent were living in the Unites States. Of this number, the third largest group, persons of Jamaican heritage, totaled 745,000 [9]. More recently, in 2023, the highest concentration of Jamaican Americans was reported living in New York (315,000) and Florida (311,000) [10]. Similarly, the Jamaican High Commission in London [11] reported 800,000 persons of Jamaican heritage living in the United Kingdom and 309,485 persons of Jamaican heritage living in Canada.

Perception of "Memory Problems" or Dementia

In 2016, Berwald and colleagues [12] explored the perception of memory problems in Black African and Caribbean British community members. Fifty informants were included in this study. Overall, the majority attributed forgetfulness as a normal aspect of the aging process.

Twelve or 24% of the participants in this study were born in Jamaica. When discussing dementia, a 43 year-old Jamaican man, living in the United Kingdom at the time of the interview stated:

> "When you talk about dementia. . . this is a White, old White people's disease, it's not seen as Black people have dementia."

An informant also noted that elders often live in their own homes and adult children may not be aware of cognitive concerns during the early stages of the disease. This may cause a delay in seeking medical care, until the disease becomes more advanced.

One person of Jamaican heritage, identified the overall sensitive nature of the problem, as a barrier to seeking help outside the family. Another informant was equally concerned about relaying sensitive information to a receptionist prior to being seen by a physician.

When seeking medical care, one informant of Jamaican heritage expressed concern that physicians seemed rushed as if they "did not have time for you." Another, specifically stated, he did not feel physicians took adequate time investigating the problem and would "just write a prescription - it's always about drugs…"

Multigenerational Picture Books as Learning Tools about Alzheimer's Disease

There is a growing recognition that persons with Alzheimer's disease (AD) are members of mutigenerational families and must be treated within context of the whole [13]. However, too often the needs of grandchildren are overlooked. Importantly, family members, including children, will directly or indirectly impact the adult with AD. For example, persons with AD have a progressive decline in their stress threshold throughout the disease process. Internal and external stressors accumulate throughout the day, when the stress threshold is exceeded the person will experience dysfunctional behaviors such as anxiety and agitation [14,15,16]. Children are likely to feel uncomfortable and even fearful when persons become confused and exhibit these behaviors [17,18]. The person with AD is receptive to nonverbal communication, and will likely sense the child's

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fear and anxiety, possibly adding to their own level of stress.

Picture books that feature a grandparent with AD, have potential as a teaching / learning tool for children and families [19]. However, such books vary by the author's level of knowledge and experience. Books must be accessed individually on both content as well as the author's background and credentials. The majority of these books feature persons of European descent. One example, written by the first author, is entitled *Musical Memories* [20]. This story applies basic principles of the *Evidence-Based Guideline: Individualized Music for Persons with Dementia*, currently in its 7th edition [21-24]. Simply stated, the primary purpose of this intervention is to alleviate or prevent anxiety and agitation by having the person listen to music that is individualized or based on personal preference and meaning. Gerdner pioneered this work in the early 1990s.

Efforts continue to expand the number of culturally diverse books with culturally responsive stories. Gerdner's first picture book, *Grandfather's Story Cloth*, a bilingual (English / Hmong) story features a Hmong American family living in the United States [25,26]. The need for this resource was identified by Hmong-American family caregivers during an ethnographic study, conducted by Gerdner and colleagues [27]. The process of making this story culturally responsive has been explained in the literature [28,29].

Another notable book, includes an African American family whose mother/grandmother lives in a nursing home. The featured intervention includes a scrapbook of memorabilia collected by Grandmother, who participated with Dr. Martin Luther King during the civil rights movement in the United States [30]. Several books have also been written specifically for members of the Hispanic community [31].

Fulfilling a Critical Need for an Illustrated Children and Family Book Embedded in the Jamaican Culture

Grandma, Don't Forget How Much I Love You [32] is the first children and family picture book that focuses on the difficult subject of Alzheimer's disease, specific to the Jamaican people. This book is intended to serve as an important learning tool for children, parents and family caregivers, living either in Jamaica or those of Jamaican heritage living in another country. The story also holds great potential for the Caribbean population. Teachers and health care professionals, who serve multigenerational families, would likely find value in this book as a teaching tool.

The authors combined their unique areas of expertise to fulfil the critical need for this story. Dr. Wtter is a family nurse practitioner with a doctorate in education. She was born in Jamaica and lived there for the first 12 years of her life, until moving to New York to be with her immediate family. Dr. Witter continues to have extended family living in Jamaica and travels there periodically to visit. Importantly, Dr. Witter helped care for her mother, who had AD, in the later years of her life.

There are different genres of picture books. This story uses a realistic fiction genre, "that portrays the real world in all of its dimensions" [33, p. 188]. This 32-page book is targeted for children approximately 7 to 10 years of age or grade levels 2 to 5. However, the underlying message of understanding and compassion transcends to individuals of all ages.

The story is about a little girl named Amancia and her grandmother who has probable AD. The Jamaican name of Amancia means unconditional love and is the underlying message of this story. Due to the serious nature of this story, Mother's presence is always near. Surprisingly Grandma's dog, Calypso, also plays a unique role as the story evolves.

The story provides an honest and respectful depiction of an older person living in Jamaica with AD, to promote understanding and compassion. It is theoretically grounded in empirical and clinical evidence for the care of persons with AD. This knowledge is translated into an age-appropriate story that is engaging and empowering to the child. The book is intended to help children cope with the challenging behaviors associated with AD and to provide a model of support to promote a positive relationship with a person who has AD.

More specifically, the story addresses issues of anxiety and agitation often associated with AD. These behaviors have been identified as stressful to children [34], other family members [35-39] and result in a decreased quality-of-life for the person with the disease [36,40]. The story is intended to help the reader identify causes for these behaviors and focus on identifying the person's preserved abilities to develop activities that promote personhood and quality-of-life.

Culturally Responsive Story

The end sheets in the front and back of the book depict a red plaid fabric with accent colors of white and blue and is referred to as "Bandana." The design also borders a small glossary of patois phrases and the author notes. This plaid is a symbol of Jamaica's history and culture. The fabric is used in the creation of the "Jamaican National Costume" and is worn with pride and distinction. The attire is reserved for national celebrations and festivals.

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Due to the serious nature of this story's subject matter, Amy Bunnell Jones, created realistic watercolor scenes to reflect and expand upon the story. This story promotes a problem-solving approach by focusing on intergenerational activities reflective of the culture. The opening scene showcases a vivid outdoor scene of Grandma Ruby's traditional bright and colorful home against the lush background of rural Jamaica. Grandma is sweeping her yard while singing hymns. A family of free-range chickens roam the yard, with a line of chicks following the hen. Tropical birds, flowers and trees adorn the landscape with a view of the Caribbean Sea in the distance. While skipping to a neighbor's home, Amancia sees Grandma working in the yard and speaks a traditional greeting in the patios dialect.

To enhance authenticity, patois phrases are occasionally sprinkled throughout the English dialogue between Grandma and family. Two examples of Jamaican proverbs are included, with each providing a significant meaning to the story. The first example occurs when Grandma leaves her Bible in the church pew, following Sunday's service. When Amancia returns it, Grandma's response reveals a deep-seated misunderstanding and stigma associated with forgetfulness in aging. This is included as a teaching opportunity, as discussed in the author notes.

In addition to verbal language, nonverbal communication is also important throughout the story. This is consistent with cultural norms in Jamaica [41]. The artist depicts sensitive facial expressions with appropriate corresponding hand and arm movements throughout the story. During times of serious discussion, characters use direct eye contact and touch. Alternatively, Grandma has a facial expression of distress, while searching for her Bible that she believes was stolen.

Church service is held in a historic stone church. Per traditional norm, both Grandma and Mother adorn their heads with a fashionable hat, for church attendance and worship. The fluttering and waving of raffia fans along with revolving ceiling fans help to convey the increased room temperature as the service advances. Within this scene we see a slight parallel between Amancia and Grandma's response to a long church service during these environmental conditions. Amancia becomes "wiggly" resulting in a nudge from Mother, accompanied by a stern look. Meanwhile Grandma begins to lose the sparkle in her eyes, while sweat becomes visible on her brow. Following the church service, Amancia appears to quickly recover. However, Grandma's response is very different. Grandma's stressors continue to accumulate during the physical activity of walking in the heat.

During their walk home, Mother and Amancia become momentarily distracted, while Grandmother continues walking. Suddenly, Amancia observes Grandma about to take a wrong turn into the sugarcane field. Amancia runs to catch up with Grandma and attempts to reason with her. However, this only causes Grandma to become more adamant that she is on the correct path. This scene provides an excellent opportunity to showcase basic principles of the *Progressively Lowered Stress Threshold Model* [14,15]. Grandma is experiencing the effect of cumulative stressors (e.g., environmental heat and physical fatigue) that results in her becoming confused.

Mother quickly arrives and realizes the need for a different approach in dealing with Grandma's confusion. Instead, Mother explains she has made Grandma's favorite meal, that awaits upon their arrival home. This provides distraction by allowing Grandma to focus her attention on a home-cooked meal of her favorite foods.

Throughout the story traditional home furnishing, such as a rattan chair and side table, add a touch of authenticity to Grandma's living room. During the noon meal, following church, Grandma sits at the head of the table, as the matriarch of the family, and leads the family in prayer. Traditional and regional food is incorporated into the story such as; purple star apples, brown stew chicken, rice and peas, steamed cabbage, sweet potato pudding and fresh carrot juice.

The value of Christian hymns in Grandma's life is a reoccurring theme, with its value emphasized near the end of the story. In the opening scene Grandma softly sings *Blessed Assurance – Jesus of Mine*, while working in her yard during the early morning hours.

The next morning, while walking to church, Amancia asks Grandma if she ate the purple star apple she picked and left on Grandma's side table while she was sleeping in her chair. Grandma replied, "I saw no fruit, I ate no fruit. What foolishness!" Her response puzzled Amancia, who remained silent with her eyes cast downward, for the majority of the walk. During church, Amancia noticed that Grandma remembered every word of every hymn and sang while swaying in rhythm to the music. These songs are part of Grandma's long-term memory and preserved abilities [22-24].

These examples precede a critical scene, where Grandma is alone in her home when she is unable to locate her precious Bible. Because it was not where she "always" kept it, Grandma assumed it was stolen by an intruder. This belief, perpetuated a catastrophic reaction leading to Grandma screaming for God's help. Amancia is nearby, while walking home from class, and hears Grandma. She runs through Grandma's front door toward the source of sound. Grandma is frantically searching in a drawer while tossing items of

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clothing over her shoulder. Amancia hears a thud and sees Grandma's Bible on the floor, partially covered by clothing. Mother arrives as this occurs and suggests they go to the living room where Grandma can sit in her favorite chair. Grandma clutches her Bible to her chest, closes her eyes, tilts her head upward and spontaneously begins softly singing her favorite hymns. In this example, Amancia and Mother remain close and receptive. Grandma knows how to access her deep faith as a means of bringing inner peace and tranquility. This is likely an approach from her long-term memory, that she has used throughout her life. This is also important because music is believed to be processed in a different portion of the brain than verbal language. Therefore, music may be used as a form of communication, even in the advanced stages when the processing of verbal language becomes impaired. This scene exemplifies how music, that is significant in the person's life prior to the onset of dementia, can be used to prevent or in this example, alleviate anxiety and agitation [22-24,42].

The end of the story concludes with an image of Grandma and Amancia embracing one another. You can feel the love between the two. On the adjacent page is a powerful image displaying Grandma's aging hands resting on the worn Bible, she has treasured throughout her life.

The story, with accompanying illustrations strive to simulate all the major senses; sight, hearing, taste, smell, and touch. Although important in all stories, here it is especially important to experience the Jamaican culture with all major senses.

- **Author Notes**

Two pages of author notes are included at the end of the book to build upon and expand important learning opportunities in this story. Author notes strive to promote understanding and awareness of AD and negate the harmful stigma that exists, as represented in a familiar Jamaican proverb. Content strives to promote a better understanding of how stressors may be reduced or alleviated to prevent dysfunctional behaviors in persons with AD.

Author notes, are intended for the adult (e.g. parent, health care provider or teacher) to enrich the learning experience by discussing content at an appropriate level of understanding for the child. Story content directly relates to and builds upon itself to strengthen its educational value. Throughout this learning experience, children should be encouraged to ask questions.

Conclusions

The authors have combined their areas of expertise to fulfil a critical need for a children and family book embedded in the rich Jamaican culture. A thorough search of the available literature was conducted to identify key concepts to be addressed. The story is intended to raise awareness, understanding, and eliminate the associated negative stigmas that may exist.

This book has dual value for both children and parents. It would make an excellent addition to school and public libraries. Librarians and teachers identify picture books. that feature children of other cultures, as providing a more global purpose by helping children learn about life in other cultures and countries [43-48].

This book was made possible by the Richard P. and Edna M. Gerdner Foundation. This foundation is also donating 500 hardcopy books to public and school libraries in Jamaica. These books will be distributed by Library Services in Jamaica. *International Alzheimer's Disease* will have access to a free downloadable e-book for their website. In addition, hardcopies of this book will be donated to public libraries in the United States, in geographic areas where large populations of persons of Jamaican heritage are living.

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