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Bilingual Comics on the Border as Graphic Medicine: Journaling and Doodling for Dementia Caregiving during the COVID-19 Pandemic

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Abstract

The use of comics can be a powerful tool to expand educational outreach efforts for improving the health and well-being of people everywhere. Dr. Ian Williams coined the term “graphic medicine” to denote the use of comics in medical education and patient care (“Graphic Medicine”). Alzheimer’s disease affects approximately five million Americans and is expected to triple to 13.8 million by 2050. Hispanics and Blacks are disproportionately affected at a higher rate than other groups (“Facts and Figures”). There is a lack of culturally relevant educational materials available for these populations. To address this disparity, an interdisciplinary community engaged collaboration was initiated with the Alzheimer’s Association West Texas Chapter, The University of Texas at El Paso (UTEP), and Dukes Comics to produce a series of virtual workshops entitled, “Journaling and Doodling for Stress Reduction and Relaxation” for caregivers of people living with Alzheimer’s and other dementias. These sessions were live-streamed and began during the COVID-19 pandemic. Spanish sessions have also been provided to the public. Health information about the disease process and common caregiver challenges are provided in each session. A guided journaling and doodling activity are also included. Journaling has been shown to be an effective and easy tool to use for stress management (Scott). The impetus behind this project was to address the dire need for increasing access to Alzheimer’s disease education and resources in El Paso, Texas, a border community that is also home to Fort Bliss Army base. Hispanics comprise approximately 82% of the population and include a large Spanish-speaking segment. Language is often a barrier to health care access and education. To meet the aim of increasing accessibility, the workshops and comics are available in both English and Spanish and soon in-person. This project received a 2022 joint seed grant from Texas Tech University Health Sciences Center El Paso and UTEP to conduct research and examine data from these workshops that will be provided in-person in marginalized and multilingual Latina communities surrounding El Paso starting in the fall.

Keywords

graphic medicine, comics, bilingual, Alzheimer's, dementia, caregiving, U.S.-Mexico border, interdisciplinary, community engaged, journaling, doodling

Imagine a seven-year-old Latina girl tugging at her mother's apron asking, "What is wrong with abuelita? She doesn't remember how to make tortillas." The mother struggles with how to explain to her young daughter that abuelita is suffering from Alzheimer's disease. The family struggles with how to deal with abuelita who sometimes shows aggression and suspicion, especially when she is feeling confused and forgetful. This is a scenario that one might find here in El Paso, Texas, where the community is primarily Hispanic and where the literacy project discussed in this article is based.

Accessibility to resources that are culturally and linguistically representative of families' lived experiences is needed now more than ever as Alzheimer's is rising and has a high impact on Hispanics and Blacks, compared to other races ("Facts and Figures"). Considering this data, and the increasing complexity of problems that affect global health, creating innovative strategies to educate individuals and communities to manage these challenges is pivotal. Therefore, working collaboratively with faculty from The University of Texas at El Paso (UTEP) and partnering with community graphic novel artists and the Alzheimer's Association – West Texas Chapter, a community-based literacy project was designed to address the need for health information that supports families from diverse backgrounds who are dealing with life-altering diseases such as Alzheimer's and other dementias. Collective efforts led to the creation of a series of virtual workshops that began during the COVID-19 pandemic titled, "Journal Writing and Doodling for Stress Reduction and Relaxation" targeted in general at caregivers of Alzheimer's patients. The workshops and comics are offered bilingually in English and Spanish language virtually to provide culturally relevant materials for marginalized and multilingual populations.

Currently, there is a lack of health literacies addressing Alzheimer's and other dementias available in languages other than English. In fact, language has been identified as a social determinant that has a major influence on healthcare access and delivery (Fiscella et al. 56; Maríñez-Lora et al. 118; Sentell et al. 290-291). Local initiatives require the help of local stakeholders who clearly understand the community, Alzheimer's diseases, and innovative approaches to reach specific audiences. Initially, the workshops featured sessions in the English language and were virtual during the quarantine in 2020. Later in this article, we provide links to the online videos. Understanding the digital divide in underserved communities, these workshops will soon be offered in person.

The Setting

Alzheimer's disease and other dementias is a growing global crisis requiring creative approaches to health literacies. According to the Alzheimer's Association, this disease affects approximately 6.5 million Americans and is expected to more than double to 13.8 million by 2050. In El Paso and Hudspeth counties, 107,459 people are aged 65 and over. After analyzing data trends, 12% of Texans aged 65+ are living with Alzheimer's or another dementia ("Facts and Figures"). When applied to the counties of El Paso and Hudspeth, it is estimated that approximately 12,895 people are affected by this disease ("Facts and Figures"). This data indicates that the disease will impact everyone living in these communities in one way or another. Communities with marginalized populations such as El Paso are especially impacted.

Situated along the U.S.-Mexico border, El Paso is one of the world's largest bi-national and bilingual metropolitan areas. Hispanics comprise approximately 82% of the population and include a large Spanish-speaking segment; in fact, two-thirds of El Paso households identify as Spanish speakers ("American Community Survey"). Language may often be a barrier to health care access and education. To meet the aim of increasing accessibility to Spanish language speakers, virtual workshops and comics in Spanish were provided. El Paso is also home to the U.S. Army's Fort Bliss post which adds to the diversity of the city. Fort Bliss documents their own population apart from the city of El Paso reporting a population with 16.7% Black and 26.6% Latino individuals ("QuickFacts"). It is evident that El Paso, coupled with Fort Bliss, is home to the populations most affected by this disease.

Members of diverse communities are more likely to endure poverty and have less access to quality health care; as a result, they are more likely to develop risk factors for Alzheimer's and other dementia such as cardiovascular disease and diabetes. Compared to Whites, studies show that Blacks are twice as likely, and Hispanics are 1.5 times more likely to develop Alzheimer's (Facts and Figures"). For these reasons, developing health literacy resources for diverse populations that address cultural, linguistic, and geopolitical factors should be considered.

Comics as Health Narratives

The use of health narratives illustrated via comics expand the accessibility of these efforts and can be a powerful tool in improving the health and wellbeing of citizens everywhere. Williams, a comics artist, physician, and founder of the Graphic Medicine website, coined the term "graphic medicine" to denote the use of comics in medical education and patient care ("Graphic Medicine"). Graphic medicine has shown to be an excellent visual health literacy resource that can provide "new insights into the personal experience of illness" (Green and Myers 574). The comics in our workshops are designed to increase the caregivers' understanding of their experience to adopt a "more considerate and enlightened attitude" when dealing with individuals living with Alzheimer's and other dementias (Williams 26). Oftentimes caregivers may not be medical professionals, and they may benefit from examples of common stressful situations, so that caregivers may understand their own emotions and learn coping

strategies. According to Squier, “graphic narrative has the capacity to articulate aspects of social experience that escape both the normal realms of medicine and the comforts of canonical literature” (130). Illustrated health narratives may provide a less intimidating source of information supplementing text-based materials.

The Origin Story —Así empezó la historia

Understanding the statistics where 59% of family caregivers of people with dementia rate their emotional stress as high or very high vs. 41% of other caregivers, Alzheimer’s Association – West Texas Chapter executive director David Hernandez, MA and Sarah Jimenez, PhD, RN, a volunteer support group facilitator, and Assistant Professor of Nursing at the UTEP, began conversations around expanding activities for support groups. Having prior experience with reflection journaling, Dr. Jimenez proposed the idea of expanding activities for caregivers and family members to reduce stress as a self-care intervention. Mr. Hernandez, with a background in art education and experience in early-stage social engagement Alzheimer’s programming, reached out to local comic book artists Elvira Carrizal-Dukes, PhD, MFA, Chicano Studies Assistant Professor of Instruction, UTEP, and artist Ronnie Dukes to assist with this endeavor. Comic book author Dr. Carrizal-Dukes led the journaling segment, while artist Mr. Dukes conducted the doodling activity. Caregivers of people with dementia are more likely than other caregivers to help with emotional or mental health problems (41% vs. 16%) and behavioral issues (15% vs. 4%) (“Facts and Figures”). Therefore, expanding support groups from only providing a forum for discussion, the activity of journaling and doodling was introduced as an additional approach to reduce stress using a series of workshops. Reflection journaling provides an outlet for participants to focus on their own personal experiences.

During the workshops, a facilitator guides participants to journal and doodle. We introduce the journaling practice and explain that journaling, or expressive writing, is a process by which one writes down thoughts and feelings. The activities of journaling enhance self-exploration and emotional processing, reduce stress, and promote relaxation (Scott). As a result, the workshops were designed and promoted to address stress relief and relaxation for caregivers. Journaling and doodling combine writing, drawing, and relaxation, exercising body and mind. It can be used as a form of therapy and can be useful during challenging times. It can be a positive distraction, an unconscious engagement with a creative activity, and a form of self-care.

The Workshops

The initial workshops consisted of one-hour sessions with a theme of common behaviors exhibited by patients with Alzheimer’s such as repetition, anxiety and agitation, aggression, and suspicion, wandering and confusion. The themes are illustrated through four-panel comics, which are called the Comic of the Day. To begin the session, the facilitator explains what journaling and doodling is, followed by a list of materials needed, such as paper and pen or pencil. Before beginning the activity, the facilitator stresses the health benefits of participation. A Comic of the Day is then in-

troduced to illustrate common stressful situations a caregiver may find themselves in when caring for an individual living with Alzheimer's disease. By highlighting these scenarios, participants may become aware of their feelings or emotions.

As the workshops were deployed, it became evident that the workshops were not reaching the Spanish-speaking segment of the local population as the workshops were being offered in English only. To expand the reach of the workshops to include Spanish speakers, the team also grew with the addition of three members: Maria Isela Maier, PhD, Assistant Professor of Instruction, Rhetoric and Writing Studies, UTEP; Jacob Martinez, PhD, RN, Assistant Professor of Nursing, UTEP; and Maria Llamas, MPA, Director of Programs, Alzheimer's Association – West Texas Chapter. The following section presents the four-panel comics and video links associated with this community literacy project. A four-panel comic is sequential art in four frames. For the purposes of this article, we are including one English language and one Spanish language four-panel comic.

The Comics

The Comic of the Day is written by comic author Dr. Carrizal-Dukes and illustrated by Mr. Dukes. The comics are hand drawn, inked, colored, and lettered by Mr. Dukes of DUKEScomics.com. They used characters from their graphic novel *A.W.O.L.* and placed them in scenes showing Cruz, the daughter, caregiving for her dad, Mr. Ochoa whom she calls *Apá*, a term of endearment used in some Latino households. In *A.W.O.L.*, Cruz is an Army soldier who leaves the military briefly without permission to find her younger brother who has been kidnapped. Mr. Ochoa is a retired United States Marine soldier who has diabetes and prosthetic legs. In the graphic novel, we also see Cruz administering his insulin for his diabetes. It's implied in the story that Mr. Ochoa has Alzheimer's or another dementia. Placing Cruz and Mr. Ochoa in these Alzheimer's scenarios felt like a natural fit.

In preparation for writing the four-panel comic strips, Dr. Carrizal-Dukes researched educational material from the Alzheimer's Association. For these comics, she focused on the common behaviors exhibited by individuals living with Alzheimer's or other dementia and reviewed strategies for caregivers on how to navigate these challenges. The behaviors presented in our workshops included anger and aggression, anxiety or agitation, forgetfulness and confusion, repetition, suspicion, and wandering. Dr. Carrizal-Dukes wrote five short scripts before the COVID-19 pandemic. Once quarantine began and as a response to heightened stress experienced by caregivers, she revised the dialogue to center on unique caregiving challenges resulting from COVID-19 restrictions.



Figure 1. Comic #1.

In this first four-panel comic labeled as Figure 1, the theme is repetition, and the script for this scenario was written before the COVID-19 pandemic. In panel one, Cruz and Mr. Ochoa are sitting at the kitchen table. They are drinking coffee. The morning sun streams through the kitchen window above the sink. Mr. Ochoa asks his daughter Cruz if his son is home, “Is Esteban home, yet?” Cruz responds, “Not yet, Apá.”

In panel two, it’s later in the day, and Mr. Ochoa is having lunch at the kitchen table. There is a glass of lemonade and a plate of enchiladas with rice and beans. Cruz is in the background walking toward her dad with a plate in her hands. Mr. Ochoa speaks first, repeating the same question. He asks Cruz, “Is Esteban home, yet?” Cruz responds, “Let’s shine your shoes before he gets home.” Dad responds, “Okay, that’s a good idea.”

In panel three, Cruz and her dad are now sitting in the living room shining shoes. Mr. Ochoa sits in a green comfy chair and Cruz sits on the floor by his feet. The dad says, “My mother would write to me when I was in the service.” Cruz responds, “That’s great, Apá. What did she write about?”

In panel four, the last panel, Cruz is alone writing in her journal at her desk. It’s the end of the day. We can assume her dad has gone to bed. There is a cup of hot tea on the table next to Cruz’ journal. She has a pencil in her hand. We see handwriting on the open page in her journal. As if reading Cruz’ thoughts, the text above her head reads “Dear Journal, When IS Esteban getting home?”

After Dr. Carrizal-Dukes reads the dialogue, Dr. Jimenez then discusses the Alzheimer’s Association four-step process to follow and apply to any behavior. In Comic of the Day, Figure 1, this is how Cruz addresses repetition with her dad, Mr. Ochoa, in this four-panel comic.

1. Who was present when repetition happened?

In this case, only Cruz and her dad are present. The son Esteban is missing, which is what is triggering her dad.

2. What happened just before and after the behavior happened?

This is a routine Cruz experiences with her dad in the morning at breakfast whenever her brother Esteban is out of town working. After the behavior happened, Cruz stayed calm. She answered her dad’s repeated question. She stays with him in his reality. Cruz distracts her dad by offering a soothing activity for her dad. Cruz participates in shoe shining with her dad. She reminds him he’s not alone. Cruz engages in conversation that is a positive trigger for her dad. This leads to him having positive feelings and memories.

3. Where did the behavior take place?

The behavior took place in the kitchen where the family usually sits together to eat breakfast. Seeing Esteban’s empty chair at the table could be triggering Cruz’ dad. Cruz moved her dad to a different room to shine shoes.

4. When does the behavior tend to occur?

It usually happens in the morning during breakfast.

5. How did Cruz react?

Cruz is patient and has gotten used to her dad asking for Esteban when he’s not home. Sometimes she’ll call Esteban on the phone before breakfast, so her dad hears Esteban’s voice. After discussing these strategies with caregivers in our workshops, Dr. Carrizal-Dukes commences the journaling exercise. She begins by bringing awareness to breathing. She guides the caregivers to take three deep breaths saying, “Inhale

deeply through your nose and exhale out through your mouth.” After doing this, she asks questions for the caregivers to reflect on. For example, what is your story with repetition and the one you’re caring for? How did you react? These questions prompt the caregiver to think about his/her own experiences dealing with repetition. The question also asks caregivers to reflect on their own actions in the real-life situation.

After a few minutes of writing, Dr. Carrizal-Dukes then prompts the caregivers to write down the opposite of what the caregiver sees, hears, or feels. The caregivers write for about five minutes, and they are instructed to write nonstop and not edit their work. Caregivers are reminded to let their hand and writing tool (pen/pencil) flow nonstop. They are told that there is no right or wrong answer. They are instructed to write honestly and from the heart and to write their own story.

Once the journaling exercise is completed, Mr. Dukes introduces the doodling exercise for caregivers and incorporates the theme of repetition during the facilitation. Like the journaling exercise, he begins with deep breathing. For this sketch diary, Mr. Dukes guides the caregiver as they begin to doodle. He starts by asking them to repeat the same drawing motion. The drawing can be a shape or an abstract idea. Caregivers can even look away from the paper or close their eyes and just do the motion repeatedly. Mr. Dukes instructs participants to always doodle lightly. When they finish, he asks them to examine what they have on the paper and make something out of it or elaborate on things that they see within the doodle. He sets a timer for five minutes and suggests to participants to doodle lightly and nonstop.

Mr. Dukes concludes the doodling segment by recommending participants to keep a daily journal and sketch diary to describe their experiences and feelings that relate to caregiving. Writing and sketching emotions can help individuals heal during stressful times. At the end of the workshop, participants are invited to share their work with other participants or on social media using the hashtags #journalingforalzheimers, #doodlingforalzheimers and #endalz. Following is a Comic of the Day written in Spanish including the script but omitting the four-step process that was already provided in English.



Figure 2. Comic #2, in Spanish

El tema de este cómic del cuidador de alzheimer, es repetición durante el tiempo de COVID-19.

Este es un cómic de cuatro paneles que presenta a una hija que cuida a su papá que tiene demencia. El papá repite la misma pregunta porque olvida que ya la hizo. En el primer panel, los dos están bebiendo café en la cocina. Apá pregunta, “¿Ya terminó COVID? Cruz le responde, “Todavía no, Apá.”

En el segundo panel, están almorzando. Y Apá repite la pregunta, “¿Ya terminó COVID?” Cruz responde, “Ahora hay una vacuna contra el COVID-19, Apá.” El Apá agrega, “No, esa es una mala idea.”

En el tercer panel, están sentados en la sala mientras el padre brilla sus zapatos, y parece que cambia de opinión sobre la vacuna. Apá comenta, “Quiero que se acabe COVID. Quiero ver a mi hijo, ir a la tienda. Creo que iré a ponerme la vacuna, Cruz-

ita.” Cruz añade, “Yo también me voy a poner la vacuna contra COVID-19, Apá. Lo hago para protegernos.”

En el cuarto panel, la hija toma té y está sola escribiendo en su diario. Escribe, “Estimado diario: ¿Cuándo terminará esta pandemia?”

It is important to note that during the workshops, along with reading the comic, we do provide strategies for caregivers to navigate these sensitive situations. However, for the purposes of this article, we have not included the discussion of the strategies in Spanish.

These bilingual Comic of the Day examples illustrate the common behaviors experienced by caregivers of individuals living with Alzheimer’s or other dementias. The comics feature individuals that are representative of the diverse population of the El Paso region. Additionally, the comics target the demographics that are most affected by Alzheimer’s and other dementias. This ongoing community literacy project was aimed at the public, but specifically for caregivers. The goals addressed were: 1) To raise awareness about Alzheimer’s and dementias’ impact on the community. 2) To provide journaling and doodling workshops for stress reduction and relaxation 3) To introduce bilingual comics as graphic medicine for caregivers promoting awareness and education and, 4) To promote journaling and doodling for relaxation and stress reduction.

Moving Forward

As pandemic restrictions are lifted, the Alzheimer’s “Journal Writing and Doodling for Stress Reduction and Relaxation” bilingual workshops will be offered both virtually and in-person throughout west Texas. Initially, we started this community literacy project in English. Considering multilingual audiences’ culture and contexts in the El Paso region and addressing the need for supplementary Spanish language health literacies, the Spanish comics and Spanish language workshops were designed to help fill this void.

Disciplinarily, our goal is to create and share educational modules like the journaling and doodling workshops with educators and students to engage with their communities through health literacies, illustrated narratives, and bilingual content. Another goal is to engage students in cross-disciplinary collaborations in which they can use their collective talents to provide health education using digital platforms. Professionally, we are developing graphic medicine geared toward families with young children to help facilitate conversations about sensitive issues such as coping with loved ones living with Alzheimer’s and other dementias. More importantly, projects like journaling and doodling workshops will help promote discourse about health literacy information aimed at bilingual and bicultural audiences. It is important to note that this innovative community literacy project was made possible with the collaboration among university faculty, nonprofit organization leaders, and community artists.

The Workshop Videos

The Alzheimer's comics and the recorded workshop series may be accessed through the DUKEScomics website <https://www.dukescomics.com/workshops>.

The two bilingual recorded workshops featured in this article, one conducted in Summer 2020 can be accessed here <https://youtu.be/F7IV6dU9TFk>, and the Spanish from Spring 2022 can be accessed here https://youtu.be/J34BB3_t1-4.

The Alzheimer's Association has a 24/7 Helpline number for caregivers: 1-800-272-3900 or visit their website alz.org. It can help to have a dementia-trained professional to talk with when you feel overwhelmed or at a loss for what to try next

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Author Bios

Elvira Carrizal-Dukes, Ph.D., M.F.A., is an Assistant Professor of Instruction of Chicana/o studies at the University of Texas at El Paso, where she teaches Chicana/o Cinema and Theatre, American Cinema of the US-Mexico Border, The Roots of Latina/o Hip Hop, and Chicano/Latino Music in the U.S. Her current teaching and scholarly projects center on Cholo consciousness, Visual Rhetoric, and Comics. To learn more, go to: www.DUKEScomics.com.

Maria Isela Maier, Ph.D., is Assistant Professor of Instruction at The University of Texas at El Paso where she teaches in the Rhetoric and Writing Studies Program in the English Department. Her teaching and scholarly projects center on language diversity, undergraduate research and community engagement in writing and pedagogy.

Sarah Yvonne Jimenez, Ph.D., RN, is an assistant professor of Nursing at the University of Texas at El Paso, El Paso, Texas where she teaches a nursing introductory course in the undergraduate nursing program. Her research focuses on stressors that affect the mental and physical health of individuals who care for family members living with Alzheimer's disease and other dementia along the U.S. Mexican border. Her scholarly projects focus on interventions that combine the arts with health education to improve health outcomes and quality of life for those living with dementia and their caregivers.

Jacob Martinez, Ph.D., RN, is a community health nurse who serves as an assistant professor at the University of Texas at El Paso School of Nursing. His research focuses on better understanding and addressing a cadre of health disparities affecting vulnerable US-Mexico Border Latinx populations.

David Andrew Hernandez, MA, serves as the Executive Director of the Alzheimer's Association West Texas Chapter. Through his leadership, he works with volunteers, staff, and supporters to further the mission across 80 counties of West Texas. The mission of the Alzheimer's Association is to lead the way to end Alzheimer's and all other dementia—by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Ronnie Dukes, A.A.S., was born on the south side of Chicago and is a comic book creator. He earned his degree in computer animation in Minneapolis before relocating to Harlem, Manhattan where he began to paint and exhibit work throughout the city. Currently based in New Mexico, Ronnie created his publishing company DUKE-Comics.com with his wife, partner Elvira Carrizal-Dukes, featuring their first major print project A.W.O.L., a full-color graphic novel available in English, Japanese and Spanish.

Book and New Media Reviews

From the Book and New Media Review Editor's Desk

Jessica Shumake, Editor

University of Notre Dame

For readers who are looking for great books to read this summer, these reviewers offer thoughtful recommendations. I wish to thank Michael J. Benjamin, Jennifer Smith Daniel, Meng-Hsien (Neal) Liu, Angela F. Jacobs, and Erin Schaefer for accompanying me on a “long journey” to see these reviews in print. The documentary filmmaker Albert Maysles, says that a “long journey” implies movement away from one’s initial starting place—to a new location—where better questions can be asked, new perspectives appreciated, and the audience carried further “spiritually, aesthetically, ethically, or whatever” (Maysles and Pryluck 9). In terms of the reviewers whose work is featured here, I’m grateful we’ve taken *ourselves* on a long journey and I’m hopeful *CLJ* readers will enjoy the ride.

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