

# Walking the talk for dementia: A unique immersive, embodied, and multi-experiential initiative

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## Abstract

Coping with dementia requires an integrated approach encompassing personal, health, research, and community domains. Here we describe “Walking the Talk for Dementia,” an immersive initiative aimed at empowering people with dementia, enhancing dementia understanding, and inspiring collaborations. This initiative involved 300 participants from 25 nationalities, including people with dementia, care partners, clinicians, policymakers, researchers, and advocates for a 4-day, 40 km walk through the Camino de Santiago de Compostela, Spain. A 2-day symposium after the journey provided novel transdisciplinary and horizontal structures, deconstructing traditional hierarchies. The innovation of this initiative lies in its ability to merge a physical experience with knowledge exchange for diversifying individuals' understanding of dementia. It showcases the transformative potential of an immersive, embodied, and

From Alex Kornhuber to Wendy Weidner are set as alphabetical order in Author Byline.

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multi-experiential approach to address the complexities of dementia collaboratively. The initiative offers a scalable model to enhance understanding, decrease stigma, and promote more comprehensive and empathetic dementia care and research.

#### KEYWORDS

dementia, diversity, experiential and immersive learning, lived experience, patient-family-oriented care, society, transdisciplinarity

## 1 | INTRODUCTION

Dementia is a complex progressive condition that impacts the brain health of individuals affected,<sup>1</sup> and may transform their identity, disrupt family dynamics, and have broader impacts on communities and health care systems. An adequate response to dementia must convey coordinated efforts across all these domains.<sup>1-3</sup> Hence, recognizing the need to foster integration among multiple stakeholders is paramount in devising holistic approaches to dementia. Traditionally, health sciences conferences serve as the nexus for sharing insights into dementia, generally led and dominated by professionals.<sup>4</sup> Experts from a specific subspecialty meet to present research findings and new perspectives to a homogenous audience of health care professionals and researchers in pre-structured lecture-style presentations, often with hierarchical structures. However, these standard conferences sometimes neglect a more holistic integration of different points of view, let alone a comprehensive inclusion of the experiences of patients and their families, thereby missing out on valuable insights. The prevailing separation between various disciplines within dementia research and care exacerbates this issue, as professionals often work in discipline-based silos.<sup>5</sup> For instance, most clinicians do not have the opportunity to engage in regular exchanges with dementia researchers or keep updated on relevant research findings. Likewise, researchers are often divorced from clinical realities and the lived experience of dementia. Part of the difficulties and delays in translating scientific advances into clinical practice are a testament to this gap, as are the many research endeavors that lack meaningfulness for people living with dementia or applicability in clinical contexts. Similarly, many policymakers rely on highly aggregated data and evidence to inform their decisions on health and care systems' responses to dementia without having had the opportunity to interact with a person living with dementia meaningfully and, therefore, better understand their care experiences. Moreover, mainstream forums can lack the necessary spaces and time for extended discussions, reflection, and co-construction of the primary needs and challenges associated with dementia.

The "Walking the Talk for Dementia" (WTD) initiative was born in response to these limitations. This unique event, consisting of a 4-day walk along the *Camino de Santiago de Compostela* (an ancient walking pilgrimage in Galicia, Spain), was followed by a 2-day symposium (Figure 1). It provided a forum for integrating views of people living with dementia, their family members, researchers, policymakers, advocates, artists, and clinicians. Attendees hailed from diverse international backgrounds and highlighted vital dementia issues while strengthening dialogue around the human aspects of researching, working, or living with dementia. In this *Policy Forum*, we describe the structure and outcomes of this initiative. We discuss its design, the experiences of the journey, the insights from the symposium, and its overall impact. Such an immersive, multi-experiential approach serves as an exemplar, emphasizing the significance of inclusivity, the power of shared experiences, collective leadership, and the need for greater integration of sciences and lived experiences in our response to dementia.

## 2 | METHODS

### 2.1 | Qualitative content creation

In the initial results section, we describe the event, capturing experiences directly from participants. This qualitative approach involved immersive interactions, notably during the walk, and non-intrusive data collection methods like discreet notetaking, audio recordings, and casual interviews. Post-event, rapid debriefing sessions garnered immediate reactions and emotions. Attendees contributed with feedback, multimedia, and art materials to create a richer narrative. The team, led by the first and last authors, used thematic data analysis, highlighting prevalent themes and unique stories. All co-authors reviewed the draft, adding insights and corrections to ensure a multidisciplinary representation.

## 2.2 | Survey generation, distribution, and data capture

### 2.2.1 | Survey development and content

A panel of professionals from diverse disciplines, including health policies, science, and lived experiences, developed the Survey. These were selected to provide a comprehensive representation, covering a broad spectrum of geographical regions (United States, Europe, Latin America, Africa, and Asia). Direct consultations were conducted with individuals living with dementia and their caregiving partners.

The Survey was constructed to capture different insights, addressing participants' satisfaction levels regarding the event, specifically focusing on its innovative features. The aim was to understand how the immersive nature of the event might positively influence participants' perceptions and understanding of dementia. The Survey inquired about personal and professional impact, insights gained, the 40-km walk and the scientific meeting, and different aspects of active and direct engagement of individuals living with dementia. The Survey also asked participants about sentiments regarding safety and comfort level in engaging in discussions encompassing a diverse array of topics during the event. It further assessed the influence of the immersive experience on the way symposium speakers crafted or adjusted their presentations.

### 2.2.2 | Survey implementation and identification

The Survey was running on the Google Forms platform. It encompassed a total of 34 questions, categorized systematically into seven sections, including "Overall experience," "The experience compared to traditional conferences," "Connections and exchange of ideas," "Perspective change," "Impact moving forward," and others. Ten days after the event, the Survey was available to 50 diverse participants. In parallel, the survey team facilitated two notification prompts within the event's participant group on WhatsApp and followed up individually over 3 weeks. The Survey included optional submission of name, email, and professional affiliations. Questions and open-ended responses were posed in a multiple-choice format to ensure comprehensive data acquisition.

## 2.3 | Data analysis

The analysis included a two-step procedure. A set of authors revised the complete Survey to extract the primary common and divergent responses via categorical analysis.<sup>6</sup> These were used to monitor the output of an automatic language analysis. Analytical strategies coupled with deep learning were used to extract meaningful insights. First, we pre-processed the raw text data, where standardization, noise reduction, and normalization techniques were used to optimize quality. Then, vectorization strategies (word embeddings and term frequency-inverse document frequency TF-IDF<sup>7</sup>) transformed textual responses for unsupervised machine learning algorithms (k-means and hierarchical clustering) and extracted patterns, segment responses,

### RESEARCH IN CONTEXT

- 1. Systematic review:** Authors reviewed literature on dementia, its societal implications, and the gaps in conventional approaches. Existing conferences and forums, primarily dominated by professionals, sometimes lack sufficient holistic inclusivity. This review showed a need for integrative, immersive, and experiential approaches to bridge the gaps between researchers, policymakers, clinicians, and people with dementia.
- 2. Interpretation:** The "Walking the Talk for Dementia" initiative is a transformative model incorporating personal, scientific, health, and community domains. This initiative included a physically immersive journey and a subsequent symposium, and emphasized inclusivity, diversity, shared experiences, and collective leadership.
- 3. Future directions:** Future endeavors should aim to scale and sustain such initiatives, integrate them into mainstream conferences, and foster transdisciplinary collaborations. It would be essential to explore how similar initiatives can be replicated in diverse cultural settings, evaluate long-term impacts on policy and practice, and emphasize the importance of patient-family-oriented care in dementia research.

and prevalent trends across data points. Natural language processing models (GPT)<sup>8</sup> were used for semantic and sentiment content via contextual analysis.<sup>9</sup> Then we created a post-analysis, central tendencies, and dispersions representing average and typical responses. This multistep approach provided a narrative interpretation of the survey data as detailed in Supplementary Data 1.

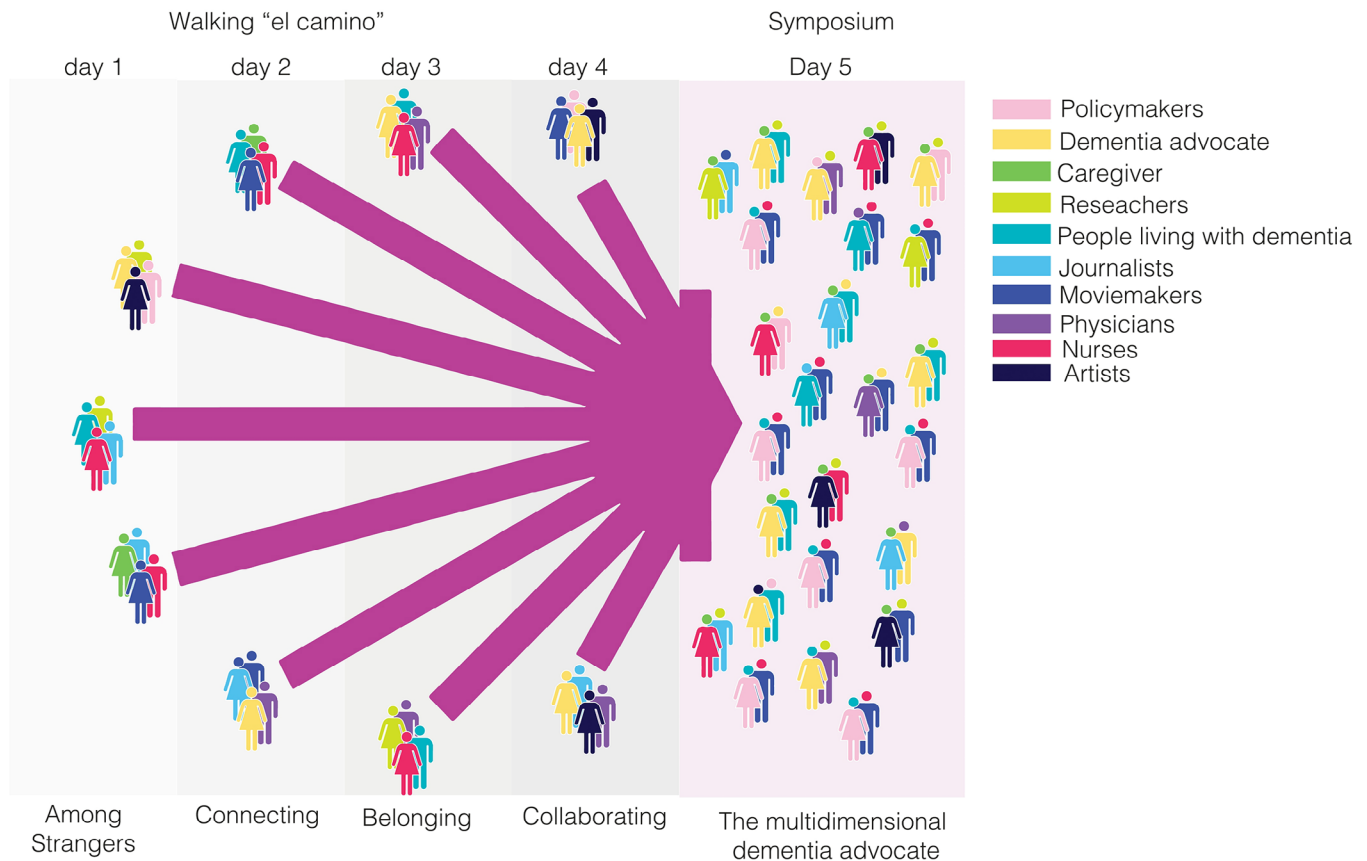
## 3 | RESULTS

### 3.1 | Walking the Talk for Dementia

The unique fusion of a physical pilgrimage and a symposium emerged as an innovative response to the existing barriers to dementia understanding and care. With participants drawn from around the globe, its primary objective was to integrate the diverse perspectives encompassing the dementia experience. Doing so aimed to stimulate meaningful discussions, promote collaborations, and bring attention to the human aspects of dementia, thereby fostering a more holistic understanding and approach.

#### 3.1.1 | The days of walking

Over 4 days, participants walked together, sharing lived experiences, knowledge, and insights, building on different discussions



**FIGURE 1** The Walking the Talk for Dementia shell. In a legendary metaphorical interpretation of the scallop shell as a symbol of the *Camino de Santiago*, lines originating from different ends converge to a common point, much like pilgrims from various places walking to a common final destination; the Obradoiro Square. The illustration below portrays the diverse participants, hailing from different countries, cultures, ethnicities, and unique life backgrounds. As the journey unfolds, these diverse individuals connect with each other's experiences, unite as a cohesive community, and evolve from being unfamiliar with isolated expertise to emerging as advocates with enriched perspectives and realms of knowledge.

about dementia from various angles. The trail began in Sarria city, with participants sharing their backgrounds and highlighting individual challenges and achievements around dementia. The group included 70 participants from 25 different countries across five continents: Latin America and the Caribbean (28.33%), North America (13.33%), Europe (38.35%), Pacific (3.33%), Asia (8.33%), and Africa (8.33%). The participants included scientists (11.11%), medical doctors (16.05%), other health professionals (7.41%), policymakers (9.88%), advocates (18.52%), people living with dementia (12.35%), care partners (8.64%), communicators (11.11%), and artists (4.94%). People living with dementia came from Singapore, Namibia, England, Ireland, the United States, and Spain. Two people had a diagnosis of Lewy body dementia and eight had a diagnosis of Alzheimer's disease, with ages between the late 50s and early 70s.

Multiple actions ensured that the experience was designed to prioritize the needs of the walkers living with dementia. Rather than staying in roadside hostels as Camino pilgrims typically do, more commodious hotel-based accommodation was arranged, with walkers bussed to each day's starting point. To consider differing levels of cognitive ability, only one hotel provided housing for all nights. In addition, participants

had access to an ambulance service throughout the route, a hired nurse walking with the group, support vehicles, and accident insurance. Another example of inclusion was the pace at which the group walked. Naturally, the large group was divided into smaller clusters walking at different speeds, organically rotating periodically to include additional participants and discuss diverse topics. However, participants were asked to walk the final route together, matching the pace of the slowest walker, thus entering the *Obradoiro Square* in Santiago as a unified group.

The group was purposefully selected to include a balance of individuals from various professional backgrounds and personal experiences, many of whom held considerable decision-making potential. This highlights the importance of involving these players who can translate the outputs into tangible actions. The ensemble comprised individuals like Berrie Holtzhausen, a former minister who is the founder and current CEO of Dementia Namibia, in Africa, now living with Alzheimer's disease himself while leading the main dementia support community in his country, and Evon Estrop, a dedicated advocate from Singapore who chose to deeply engage with her husband's Alzheimer's diagnosis, becoming a pivotal figure in Alzheimer's advocacy within her

community. Notable attendees included Clara Dominguez, a neurologist and host from Santiago, and Fernando Aguzzoli-Peres, a brain health communicator from Brazil whose inspiration pioneered the event.

Their journey commenced with a 10-km walk from Sarria to Portomarin, joined by a group of individuals with dementia and advocates from the Alzheimer's Association of Santiago de Compostela (AGAEDA). In the next 3 days the group walked for about 10 km per day, totaling 40 km. Engaging discussions flowed effortlessly among the walkers, while they shared their unique perspectives on dementia experiences. Contributions from participants such as Lebo Molete, from South Africa, highlighted linguistic barriers encountered in African languages when discussing dementia. Agustin Ibañez, from Latin America, emphasized the crucial meaning of communities bridging academia with other fields, such as the arts, in pursuing more inclusive and equitable research design, highlighting his efforts in building such networks in Latin America. Desmond O'Sullivan, an advocate for Lewy body dementia, shared his passion for educating others about his journey while living with the diagnosis. Over the following days, the group expanded to include neurologists and neuroscientists from other regions. Poignant narratives about the stigmatization of patients with dementia around the globe were shared, including witch-labeling in Africa. The informal and relaxed setup allowed for free conversations between participants. These stories stirred emotions and fostered deeper connections amidst the exhaustion and adverse weather. The group burgeoned to nearly 300 participants in purple shirts by the final day, involving people living with dementia and advocates from various parts of Galicia gathered by the Alzheimer's Federation Galicia (FAGAL) to walk the last kilometers with the international group.

The journey challenged the physical and psychological endurance of the participants. Because the group included individuals with different levels of motor and cognitive ability, the logistics were organized so that everybody could complete the walk, with various forms of physical and psychological support throughout the journey. As the walkers made their way into Santiago, they were greeted with overwhelming backing and celebration by tourists, pilgrims, and locals through the narrow alleys of the old city. This shared commitment and dedication to illuminating the human side of dementia fuels their continued efforts toward this profound cause.

### 3.1.2 | The symposium

Following the walk, a symposium featured presentations and discussions on various dementia-related topics. All participants had a chance to present their stories and projects. Topics included health disparities, non-drug interventions, diagnosis, and ways to change the stigma narrative, discussed by a mix of key players, giving prominence to people living with dementia in different roles (Figure 2). In line with Patient and Public Involvement (PPI),<sup>10</sup> the project actively engaged individuals with dementia in shaping the event's design, decision-making process, scientific agenda, and logistics. People living with dementia were assigned a variety of occupations, showcasing their diverse skills, and

promoting an equitable distribution of responsibilities. For instance, Laurie Waters, who had been part of the event's design, spoke at the symposium about her experience living with Alzheimer's. She also skillfully moderated a panel discussion on dementia awareness with three other participants. This highlights the effective integration of PPI principles to ensure genuine representation and meaningful participation of those directly impacted by the topic.

The symposium developed as a natural continuation of the informal conversations held during the walk together, allowing a structured space for discussion. The symposium was organized into nine main topics:

1. *Addressing health disparities: reducing the inequitable impact of dementia* was the first topic. Here, presenters discussed various examples of health disparities and potential policy actions to achieve health equity. Maria Teresa Ferretti (Austria/Italy) of the Women's Brain Project<sup>11</sup> (WBP, Switzerland) highlighted the disparities in dementia experiences and treatment between men and women. As the disease presents differently across sexes and genders (and overwhelmingly affects women), she called for a policy shift to acknowledge and address these differences. Specific populations might be at higher risk of dementia, requiring ad hoc measures. In this context, Michelle Steele (Australia) discussed the higher prevalence of dementia among Indigenous Australians,<sup>12</sup> attributed to six modifiable risk factors that specifically affect this population. She highlighted cultural considerations and the need for Indigenous-inclusive health strategies. As remarked by Wendy Weidner of Alzheimer's Disease International<sup>13</sup> (UK), National Dementia Plans are key in providing a framework for action and accountability to address such disparities. She mentioned the #WhatsYourPlan campaign to advocate for implementing such plans.
2. The second topic was *non-drug interventions: the role of arts and creativity*. The *Camino* offered a unique opportunity to learn about innovative interventions that can integrate traditional care pathways—from music to virtual reality. Laura Navarro Ramón (University of Santiago de Compostela, Spain) presented *Sensogenomics*,<sup>14</sup> exploring the impact of music on health, with pilot studies showing differential gene expression in Alzheimer's patients before and after a musical experience. Sara Marsillas (Matia Institute of Gerontology, Matia Fundazioa, Spain) discussed "Dementia in Cultural Mediation," highlighting the potential of cultural activities for social inclusion in dementia care.<sup>15</sup> David de Jong (The Netherlands) described *VR Bieb* as a Virtual Reality solution<sup>16</sup> for care worker training, co-designed with users to enhance empathy and patient experience. Evon Estrop (Singapore) shared her experience living with dementia, highlighting the importance of advocacy and support groups. Alexandre Kalache (Brazil) emphasized qualitative outcomes like quality of life improvements and anti-ageism actions.<sup>17</sup>
3. Then, *living with dementia: different perspectives* started with Laurie Waters (USA), who shared her journey from early onset Alzheimer's diagnosis to becoming an advocate, emphasizing the need for personal connection. Berrie Holtzhausen (Namibia) discussed his



**FIGURE 2** Images of the walk and the symposium. The panel showcases different moments of a week-long immersion in diverse dementia-focused experiences, transitioning from strangers to kindred feelings, forming a united community driven by a common purpose. Moving from left to right, first row, Terri Montgomery, living with Alzheimer's in Chicago, USA, walking and engaging with other event participants. Further along, Temitope Farombi, a Nigerian neurologist, celebrates alongside José Garcia and Joaquina Garcia, both Spanish and living with Alzheimer's. In the second row, the group arrives at Obradoiro Square, the destination of the pilgrimage, where Kevin Quaid, living with Lewy body dementia in rural Ireland, kneels in jubilation upon reaching Santiago de Compostela. The four images in the last two rows depict interactions during the symposium, where the stage was shared among people living with dementia, advocates, policymakers, researchers, artists, and clinicians, presenting their work and solidifying vital topics.

advocacy work against stigmatizing dementia patients as witches in Namibia.<sup>18</sup> Kevin Quaid (Ireland) urged researchers to listen to dementia patients.<sup>19</sup> Charles Dupont (Belgium/The Netherlands) and Fernando Aguzzoli (Brazil) emphasized the need for dementia patient and caregiver involvement in the dementia narrative<sup>20,21</sup> and financial support for PPI.

4. The topic *building an ecosystem: connecting for thriving* focused on the importance of collaborations and innovative models to change the current status quo. It began with Agustin Ibanez (Argentina/Chile/Ireland), who discussed three critical aspects: isolation, collaboration, and radical collaboration, using his experience in dementia research in Latin American underserved populations<sup>22–28</sup> and with his father as an example of dementia challenges.<sup>29</sup> Ishtar Govia (Jamaica) spoke about health care system preparedness in Jamaica and the importance of international collaborations.<sup>30</sup> Dominika Suchonova (Belgium) discussed the

RETHINKING Alzheimer's disease, a European Brain Council-led project to foster early diagnosis and awareness.<sup>31</sup>

5. The topic, *dementia awareness: how to change the stigma narrative*, was the final topic of the first day and started with Lebo Molete (South Africa), Atlantic Fellow for Global Health Equity, who underscored the pressing need for a national strategy to tackle dementia in South Africa, which is burdened by the stigma of witchcraft and lack of health literacy.<sup>32</sup> He lauded local radio as an essential tool for increasing the awareness and understanding of dementia. Temitope Farombi (Nigeria) shared her harrowing experiences as a neurologist, clinical neuroscientist, and dementia advocate, dealing with the fallacious witchcraft accusations against dementia patients.<sup>33</sup> Farombi, herself falsely accused of promoting witchcraft, leads the campaign, "Dementia not witchcraft," aiming to rescue, rehabilitate, and reintegrate victims.<sup>32</sup> Melissa Chan (Singapore/Luxembourg), Atlantic Fellow for Global Brain Health, shared her journey with

her father's dementia diagnosis, highlighting the emotional struggles her family faced. Chan develops community-based solutions, like the CARA app, to aid people living with dementia. She also spearheads a Brain Health Programme in Luxembourg to promote workplace brain health and is working to adapt and bring an advocacy program for lived experiences.

6. In the topic *care partnerships: a transformational experience*, Helena Quaid (Ireland) emphasized the emotional and physical toll of being a care partner for a person with dementia. She underscored the need for self-care and the importance of empathetic care and support. Ton in 't Veen (The Netherlands) shared the profound changes he experienced as his wife's care partner following her diagnosis of early-onset Alzheimer's. He highlighted the necessity of open discussions about end of life with a person with dementia. Elaine Mateus (Brazil) shared findings from her "Portraits of Care" study,<sup>34</sup> underscoring the importance of personalized support for care partners with varying experiences and needs.
7. The subsequent topic was *how we are diagnosing dementia in 2023*. In Costa Rica, Randall Perez has developed a young-onset dementia service to address diagnostic challenges. Meanwhile, in Brazil, Eduardo Zimmer outlined the potential of blood biomarkers to diagnose Alzheimer's<sup>35,36</sup> in low- and middle-income countries. After that, Des O'Sullivan (England/Ireland) shared his journey living with Lewy body dementia, stressing the importance of early detection.<sup>37</sup>
8. In the next topic, *dementia across cultures: how culture influences the dementia pathway*, Rianna Patterson (Dominica) and Khanyo N Ngcobo (South Africa) discussed the cultural complexities and disparities in dementia care in the Caribbean<sup>23,38–42</sup> and sub-Saharan Africa,<sup>32</sup> respectively. Patterson champions youth-led dementia education, while Ngcobo calls for improved pathways involving traditional healers for dementia care. Alexander Kalache (Brazil) addressed the intersection of ageism and stigma against mental health, calling for a collective stand against ageism.<sup>17</sup>
9. The final topic was *dementia policy: where to start if there is a priority*. In dementia policy, Iracema Leroi (Ireland) stressed the importance of PPI<sup>43,44</sup> in the research cycle, promoting the co-creation of knowledge by researchers and stakeholders. Stefania Ilinca (Romania/Denmark) reflected on health and care system readiness<sup>45</sup> for a disease-modifying treatment and key investment areas to boost system preparedness. Afterward, Jesús Rodrigo Ramos (Spain) discussed Spain's national dementia plan,<sup>46</sup> emphasizing the need for adequate funding to achieve its goals.

### 3.2 | Multimodal impact

The initiative has amassed considerable reach since its inception. It has welcomed more than 300 attendees for different activities during the week. Participation from research and academic institutions (ISTAART—Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment, Universidade de Santiago de Compostela, BrainLat Institute at Universidad Adolfo Ibáñez, Dublin City University, Matia Institute of Gerontology, ReDLat and LAC-

CD consortia, Atlantic Philanthropies), advocacy groups (Associação Crônicos do Dia a Dia, Sociedade Galega de Neurologia, Dementia Singapore, Federación Alzheimer Galicia, AGADEA, Project We Forgot, Febraz, CEAFA, World Young Leaders in Dementia, Atlantic Fellows, and African Brain Health Network), and policy-making bodies (European Brain Council, Alzheimer's Disease International, International Longevity Center Brazil) further underscored the initiative's reach.

Case studies showcase the profound benefits of this experiential approach, highlighting different aspects of an event that built a community. Peter Estrop (Singapore), diagnosed with Alzheimer's at age 60, emphasizes empathy and the power of connections (Box 1). Laurie Waters (USA), diagnosed with Alzheimer's at age 52, describes the importance of a sense of belonging (Box 2). Valli Yanni (UK), the caring partner of Desmond O'Sullivan, who lives with Lewy body dementia, stresses the significance of feeling safe and cared for (Box 3). These case histories illustrate this initiative's transformative impact on people living with dementia, their families, and communities. From personal tales of resilience and inspiration to a deeper understanding of the daily challenges that caregivers face, these case studies shed light on the lived realities of dementia and how an immersive, experiential approach can empower and inspire those affected by the disease.

#### 3.2.1 | Survey results

A comprehensive survey (Figure 3 and Supplementary Data 1) was conducted to quantify the initiative's overall impact. The main survey results reflect the profound influence the initiative has had across various domains. The Survey highlighted significant improvements in participants' understanding of dementia, increased empathy toward people living with dementia and care partners, and a greater willingness to advocate for dementia-friendly policies. It also underscored the initiative's success in fostering productive, interdisciplinary dialogues and collaboration. Moreover, most respondents expressed their desire to continue and expand such immersive, integrative events in the future, testifying to the value and relevance of this unique approach. These impacts are cutting across personal, scientific, and public health domains. In terms of public health, the initiative creates awareness and enhances societal understanding of dementia, thereby decreasing stigma and fostering dementia-friendly communities.

## 4 | DISCUSSION

The initiative uniquely combined physical activity with thoughtful discussions, promoting immersion, multi-experiential learning, and embodied approaches.<sup>47,48</sup> It complemented traditional conference boundaries by fostering a safe and empowering space where lived experiences were given as much importance as scientific research. This approach facilitated the generation of prosocial values,<sup>49</sup> such as empathy, understanding, and solidarity among participants, thereby further enriching the dialogue around dementia.

**BOX 1. Case history: Peter Estrop, Singapore**

In 2020, at the age of 60, I got the news that I was diagnosed with Alzheimer's. It was the biggest shock of my life, and it scared me. Before the Walking the Talk for Dementia (WTD) event even began, its value became clear during my training in Singapore. This experience highlighted how strong my wife is for joining me on this journey. Memories of my career in the Singapore Armed Forces, our military marches, and my sense of mission flooded back. WTD was thoughtfully orchestrated, providing moments of introspection amidst connections with fellow participants. Through this framework, bonds were forged, ideas sparked, and the exchange of our dementia experiences lifted my spirit. The presence of those embracing life wholeheartedly, despite their condition, resonated deeply. Among the myriad personal experiences during this journey, one stood out. During one of my mood swings, the perceptive observation of David, a fellow WTD participant, prompted him and his dog Truffles to accompany me, offering a calming and reassuring presence. Their empathy served as a genuine source of comfort. The phrase "I Don't Know, What I Don't" evolved into "I Know what I Don't Know," encapsulating the profound transformation that WTD brought about. This event was a remarkable journey of transitioning from a state of uncertainty to acknowledging the vast scope of what I still had to learn—underscoring the importance of connecting with individuals who share lived experiences. The visionary concept behind WTD, fostering informal connections, proved ingenious. It sowed the seeds of a close-knit community that I eagerly anticipate seeing flourish through more WTD gatherings worldwide.

The discussion about dementia saw active participation from a wide range of domains, including those indirectly implicated, such as the convergence of art through dance and technology through virtual reality. The collective dedication and commitment of all participants brought a wealth of diversity. From stories of personal experiences with dementia to sharing initiatives for supporting the dementia community, each participant brought something unique to the journey.

The walk was a literal and metaphorical journey, symbolizing an embodied collective endeavor to understand and tackle dementia. It offered a horizontal space where all participants could engage in meaningful conversations regardless of background. This contrasted traditional vertical hierarchies observed in some scientific or clinical conferences. The experiences shared during the journey varied greatly, reflecting the inclusive nature of the initiative. The event successfully integrated better science, appropriate interventions, and lived experiences to foster a more comprehensive understanding of dementia, establishing a basis for subsequent interpretation and discussion. Furthermore, scientists, researchers, and academics who participated in

**BOX 2. Case history: Laurie Waters, United States of America**

When I was diagnosed with dementia at the age of 52, I thought my life had ended, and I naturally felt alone; after all, I was young, and this wasn't the story I knew about Alzheimer's. The Walking the Talk for Dementia (WTD) experience has been life-changing to me. It has shown me that I'm not alone in my journey with dementia, connecting me with people worldwide who are thriving despite their diagnoses. Through WTD, I've shared my story with researchers and learned from theirs, realizing that my voice can influence their work for future generations. I feel that I now have a better understanding of how the minds of researchers and policymakers' function, and hearing caregivers' diverse stories inspired me to organize aspects of my future, guided by their examples. WTD has empowered me to ask for and accept help. In situations of vulnerability during the event, I learned the strength in seeking assistance, overcoming the fear of needing help that often holds us back. This lesson is essential: it's okay to ask for help to achieve things, but not ok to let dementia define our lives. Supported by friends and family, I now believe I can accomplish anything, regardless of my diagnosis. The impact of WTD is evident in my decision to get my first tattoo at 58, six years into my journey with Alzheimer's. I now have something on my body to remind me of this great adventure. This initiative has taught me that my voice matters, and I promise I will be loud and clear when advocating for my rights. I have renewed my purpose, and the courage to face each day with hope and determination.

the walk and presented at the symposium expertly managed to pitch their technical language to a level accessible to fellow participants, observing the principle of inclusivity and collectivity.

This approach gave participants a unique lens to somatically, cognitively, and empathically embody an international immersion experience. This involves several methodological issues that include (1) *the organizing of an effective short-term intercultural immersion and collective symposium to gather repositories of knowledge for purposes of shareability*; (2) *a co-combining of verbal communication and sensory observation*; (3) *the inclusion of different units of analysis in terms of patients, researchers, and practitioners, which reflects a multi-stakeholder approach*; and (4) *the fostering and expansion of action-oriented approaches to research*. The initiative is sympatico with ethnography in its recording of human action in a natural setting, the experiential participation that occurs in a special cultural context, the deriving of informed etic and emic interpretations that embrace and explain cultural variations, and the use of walking as a method of inquiry, not solely for knowledge creation, but for problem-solving at both localized and scalable levels.



**BOX 3. Case history: Valli Yanni, Desmond's O'Sullivan Care Partner (England)**

I am Valli, the other half of Des, who is living with Lewy body dementia. We were still kind of buzzing about the WTD and the whole experience with the Camino, all the wonderful people that we met, and all the reflections, insights, connections that we made there. As a journey care partner, it is important to stress that I felt safe. Everybody felt safe in everybody's company. As a result, I didn't feel I had to be with Des all the time. I knew that he was walking a certain distance at his own pace with different people. I kind of let go, as I fully trusted everybody else. It's not about receiving support because of having dementia; he was part of the gang. We were. Everybody had their own needs, and Des had his, and that's okay. Everybody was keeping an eye on Des at different stages, and he had time to connect with different people without me. When coming back home, we couldn't stop talking about it. It was an adventure that brought us to life, and I feel that it did the same for all of us. We had a session with the family and showed them some of the videos and pictures. But also, we talked to Alzheimer's Research UK, Dementia UK, and other organizations, because the Camino lives on, and it has to keep on living. The diversity of the Walking the Talk for Dementia made Des and me realize the importance of bringing our stories and others closer to science, bringing these life experiences to the center, the heart of everything that is done for us. So don't do anything without having the people living with dementia and their families in the center.

**4.1 | Benefits of the experiential approach****4.1.1 | Connecting and leading by example**

The initiative enabled a shift from transactional to experiential knowledge, transforming dementia conversations into meaningful actions and providing a platform for mutual learning, unscripted interactions, and shared reflection. No introductions were done at the beginning of the walk, fostering an organic connection and conversation and removing pre-conceived barriers. An example of this would be a researcher walking alongside another participant with whom they had engaged in a discussion about research ethics, only to discover later that the participant was living with dementia. This experience may expand the physician's concept of a patient's capabilities.

**4.1.2 | Open discussions for deeper understanding**

For many professionals, especially from low- and middle-income countries (LMICs), this may be the first opportunity to discuss demen-

tia diagnosis with someone living with dementia openly. Numerous countries in the southern hemisphere face significant levels of underdiagnosis<sup>50</sup> due to socioeconomic inequality, cultural stigma, and poor attention to dementia by physicians, resulting in delayed diagnosis and hindering open conversations about the topic. This experiential approach facilitated a profound comprehension of the multifaceted nature of dementia, stimulating a change in mindset driven by lived experiences toward more integrated, empathetic care.

**4.1.3 | Building a community**

An essential aspect of the initiative was the creation of a safe, trusting, and empowering community. The shared physical journey and open exchange of stories and experiences fostered an environment of mutual respect but also reciprocal care. In a practical example, some participants with a dementia diagnosis felt tired at specific challenging points of the walk, choosing to advance a few kilometers in a support vehicle provided by the logistics team. However, their journey companions felt safe walking with the larger group, trusting those who had stayed with their loved ones. Often, these journey companions would be found separated from their spouses, walking at different paces and kilometers apart, as they knew other members of this caring community would join their loved ones. This setup enabled participants to express their fears, aspirations, challenges, and successes related to dementia openly.

**4.1.4 | Embracing vulnerability**

The walk and talk became a powerful therapeutic tool as the shared vulnerability played a significant role. By embracing vulnerability, participants created an environment where egos were left behind, fostering genuine connections. This catalyzes building an environment of trust within a supportive community. The walk challenges participants to step out of their comfort zones, pushing their bodies and minds in a journey where personal achievements hold less significance than the group's accomplishments. Ultimately, this contributes to a movement that strives to reshape narratives surrounding dementia care.

**4.1.5 | Equitable engagement for nurturing inclusive conversations**

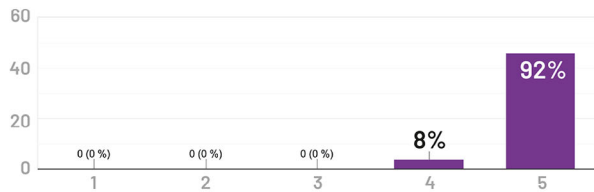
The walk-and-talk event's structure effectively established an egalitarian environment, valuing each voice equally. Whether from people living with dementia or professionals, every perspective found recognition and appreciation. This disruption of hierarchy fostered a more democratic and inclusive discourse on dementia, encouraging novel and invaluable insights. Simultaneously, it facilitated a transdisciplinary, patient-family-oriented approach that contrasts traditional medical conferences. This integration of perspectives spotlighted the

(A)

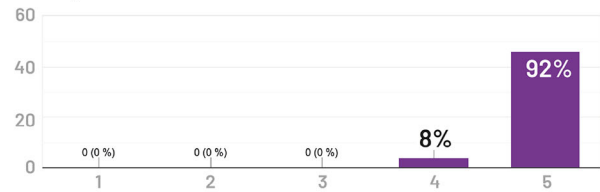


(B)

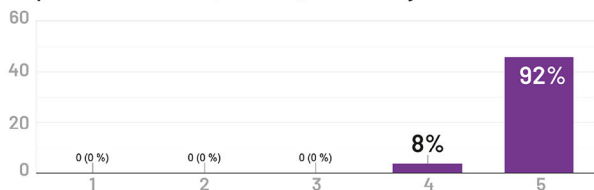
How would you rate your overall experience at the "Walking the Talk for Dementia" event?



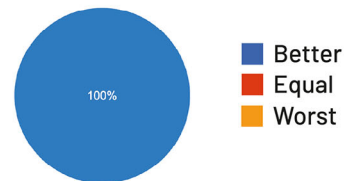
Did you find the combination of the 4-day walk and the 2-day symposium to be a unique and valuable experience compared to a traditional conference?



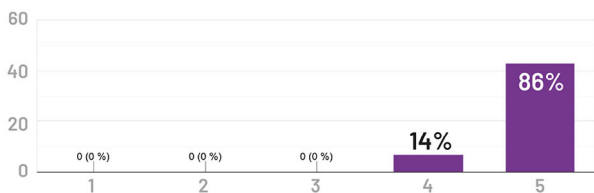
Did you feel that the immersive nature of the event allowed for a deeper reflection and understanding of dementia and its impact on individuals, families, and society?



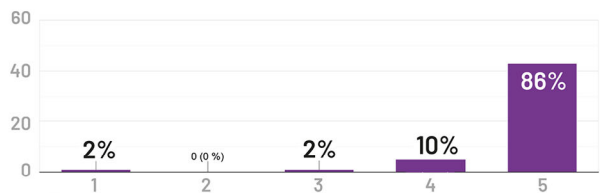
Compared to classical conferences, this initiative was:



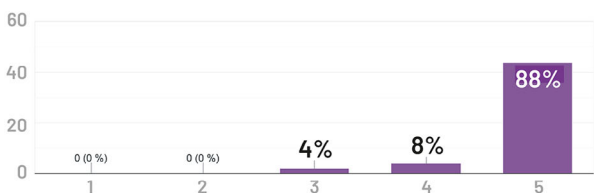
Compared to other conferences, how different was this initiative?



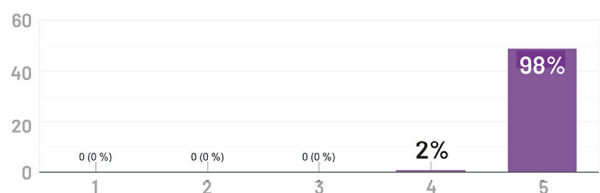
Were you able to meet and interact with a diverse group of individuals from different backgrounds and countries during the event?



Did you feel that the event encouraged collaboration and the exchange of ideas across disciplines?



Would you recommend this type of immersive and experiential event to others interested in dementia care and research?



imperative for a patient-family-centric approach to dementia care, emphasizing caregivers' pivotal role<sup>21</sup> and the need for interventions that address their challenges.

#### 4.1.6 | Communicating effectively

The immersive walking experience involving the symposium speakers and their audience yielded an intriguing phenomenon, as many presentations were altered based on the interactions. After returning from the daily walk with the group, all speakers revisited their slides and narratives for the concluding symposium, aligning the content to better connect with the audience's needs.

### 4.2 | A plan for scalability and sustainability

As the initiative continues to impact the participant's ecosystem significantly, it becomes imperative to consider its scalability and sustainability. The global burden of dementia is projected to rise dramatically, especially in the Global South,<sup>50</sup> necessitating the broader reach of such transformative, multidimensional approaches. The initiative must evolve to meet the growing need for comprehensive, inclusive, and empathetic dementia care and research, reaching wider audiences and adapting to various sociocultural contexts. There are multiple aspects identified to grow this initiative.

#### 4.2.1 | Continuity

A critical component of the initiative's scalability is maintaining continuity. This includes preserving the core ethos of the initiative—integration of diverse voices, creating safe spaces for deep conversation and connections to form, and fostering transdisciplinary dialogues, while expanding its reach.

#### 4.2.2 | Geographical and cultural expansion

The initiative must expand beyond its original geographical boundaries for sustainability and broader impact. This implies hosting immersive experiences combined with scientific symposia in varied global regions, adapting to cultural specificities, and ensuring inclusivity across diverse sociocultural contexts.

#### 4.2.3 | Technological amplification

Technological solutions offer immense potential to expand the initiative's reach. Live streaming of walks and symposia can bring the experience to those who cannot physically participate, creating a globally connected community. Technological advances like augmented reality could be used to record shared walks, offering participants the opportunity to relive the experience or to allow those who could not attend to participate virtually. In addition, the event had some members from the local community and other national representatives who did not speak English. Although this did not hinder interaction with the larger group, forming a supportive network of individuals willing to translate and support, WTD could utilize technological tools for simultaneous translation, making it easier for additional participation.

#### 4.2.4 | Funding and sustainability

Securing consistent financing is crucial for long-term expansion. By demonstrating its significant impact, the initiative can attract sponsorship from health care organizations, philanthropies, research institutions, tourism agencies, and governmental bodies. The funds can facilitate geographic and technological expansion, ensure accessibility for diverse participants—especially from the Global South, and support ongoing research and advocacy efforts stemming from the initiative.

## 5 | CONCLUSIONS

*Walking the Talk for Dementia* complements traditional conferences on brain health and dementia. Where traditional formats sometimes restrict the involvement of people living with dementia and care partners and interdisciplinary connections and collaborations, this initiative champions inclusivity, diversity, empathy, and collaborative exchange and learning. It bridges divides between different stakeholders and actively engages those directly impacted by dementia, setting a new precedent for holistic understanding and action in the field. In the hustle of traditional conferences, time for deep reflection is sometimes lacking. The initiative integrates time for contemplation, fostering personal and collective insights, nurturing relationships, and enhancing commitment toward dementia-related challenges. This reflective space aids in moving from mere transactional knowledge to experiential understanding, promoting a more empathetic, patient-centered approach.

**FIGURE 3** Main results of the Survey. A post-event survey was collected among 50 attendees. (A) Background of the participants. (B) Selected specific questions results (see Supplementary Data 1 for full survey results). The event has been a transformative experience for participants. The shared journey fostered empathy and mutual respect, creating a safe environment for open dialogue. Participants appreciated the opportunity to meet with diverse individuals from different backgrounds and countries. Despite room for improvements, the event has been largely praised for its structure and organization. The participants reported significant changes in their perspective, motivation, and understanding of dementia. (For a detailed description of the survey results, see Supplementary Data 1.)

In summary, a pioneering model for tackling dementia, integrating diverse perspectives, fostering deep reflections, and designing effective strategies was created. As we look ahead, it is crucial to scale and sustain this initiative to transform dementia care and research globally. Its potential to enhance the lives of people living with dementia and their journey partners is profound, and its influence in the broader health and social care sectors is bound to be transformative.

## AUTHOR CONTRIBUTIONS

F.A.P., C.D., and G.S.M. designed and organized Walking the Talk for Dementia. A.I. prepared the initial draft and integrated the authors' contributions. Figures 1 and 2 were created by E.Z. and F.A.P. The Survey was designed by F.A.P., A.I., M.C., K.N., and M.S. Figure 3 was created by A.I. Case histories were written by L.W., P.S., and V.Y. A.I. and F.A.P. carefully revised the draft. All authors contributed to the contents of this article and approved the final version.

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### CONFLICT OF INTEREST STATEMENT

M.T.F. is the co-founder and former Chief Scientific Officer of the Women's Brain Project. In the past 2 years she has received speaking and consultancy fees from Roche, not related to this project. The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest. Author disclosures are available in the [Supporting Information](#).

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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