

## Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a Space of Social Resistance

Giulia Alonzo<sup>a</sup>

### Abstract

This article investigates the Alzheimer Fest, an annual itinerant cultural event in Italy, as a unique case study in the representation of dementia through festive modalities. Drawing on ethnographic fieldwork conducted between July and October 2024, including participant observation and in-depth interviews, the study explores how Alzheimer Fest challenges the stigma associated with Alzheimer's disease and fosters inclusive practices of cultural welfare. Grounded in a socio-symbolic approach, the paper situates the festival within broader debates on public health, citizenship, and the role of cultural participation in reshaping dominant narratives around illness and care.

By merging the celebratory atmosphere of a festival with the sensitive theme of neurodegenerative disease, Alzheimer Fest functions as a counter-hegemonic space that reconfigures public perceptions of vulnerability. The event offers a pluralistic platform where people with dementia, caregivers, health professionals, and the wider community engage in aesthetic, relational, and performative practices aimed at recognition and social inclusion. Through theatrical performances, art exhibitions, workshops, and public testimonies, the festival restores voice and visibility to marginalized identities, fostering a relational model of care that transcends institutional boundaries.

The findings highlight the festival's role as a laboratory of participatory welfare and an engine of cultural advocacy. Rather than being a temporary celebration, Alzheimer Fest emerges as a generative process that produces social ties, symbolic reconfigurations, and enduring community networks. The paper ultimately argues for the integration of such cultural interventions within public strategies for dementia care and stigma reduction.

Keywords: Dementia, stigma, festivals, Alzheimer fest

---

<sup>a</sup> University Cattolica del Sacro Cuore, Italy

Corresponding author:  
Giulia Alonzo  
E-mail: giulia.alonzo@unicatt.it

Received: 21 July 2025  
Accepted: 24 November 2025  
Published: 24 May 2026



Copyright rests with the author/s. This is an open access, peer reviewed article published under the Creative Commons License (CC BY 3.0).

## 1. Introduction

Alzheimer's disease today represents one of the most significant health and social challenges of our time, not only due to the growing impact associated with population aging, but also because of the symbolic and cultural burden it carries. According to data reported, the World Health Organization (WHO, 2024) estimates that more than 57 million people worldwide are affected by some form of dementia. In Italy, the Dementia Observatory, coordinated by the Istituto Superiore di Sanità (ISS), reports that approximately 1,100,000 individuals live with a form of dementia, of whom 50–60% have been diagnosed with Alzheimer's disease, amounting to around 600,000 people.

From a medical-clinical perspective, dementia is currently defined in the DSM-5 as a neurocognitive disorder, a syndrome characterized by a significant decline in cognitive functions (memory, reasoning, language) that impairs functional autonomy and social relationships (Bianchetti & Trabucchi, 2010). Alzheimer's is the most common form of dementia in Western countries and is classified among the neurodegenerative dementias: a group of pathologies involving the progressive death of neurons, for which no definitive cause or curative treatment is currently known (Tremolizzo & Ferrarese, 2008). The onset of the disease is often subtle and difficult to detect, with a slow progression that ultimately leads to irreversible cognitive decline and loss of the ability to live independently (Mecocci et al., 2002). The average duration of the illness is estimated to range between 5 and 12 years, and it is considered the seventh leading cause of death globally (Italian Ministry of Health, 2022).

The ways in which Alzheimer's disease is represented, communicated, and experienced deeply affect the quality of life of those involved and the societal response more broadly (Cheston et al., 2018). Within this framework, the present study seeks to investigate the role that cultural festivals may play in reshaping social representations of dementia, in promoting advocacy, and in enhancing caregivers' well-being. Drawing on the ethnographic analysis of Alzheimer Fest, an itinerant event held annually since 2017 in various locations across Italy, aimed at destigmatizing the disease, this paper explores the participatory, communicative, and symbolic dynamics activated during the festival. The aim is to understand whether, and to what extent, such initiatives may function as public spaces of resistance to stigma and as generative contexts for new forms of active citizenship and social inclusion.

## 2. Background

### 2.1. *The Stigma of Alzheimer's Disease: A Socio-Cultural Perspective Between Theory, Narratives, and Practices of Exclusion*

The theoretical framework of stigma developed by Erving Goffman (1963) provides a crucial analytical lens for understanding the social dynamics surrounding illness, identity construction, and public perception. In his classic work *Stigma: Notes on the Management of Spoiled Identity*, Goffman defines stigma as an attribute that deeply discredits an individual, who is perceived as compromised, devalued, or inferior. This devaluation does not reside in the attribute itself but is socially constructed through interactions that assign it meaning. Goffman distinguishes between visible stigmas, such as evident physical disabilities, and invisible or concealable stigmas, including mental or chronic illnesses. The latter, often less immediately recognizable, place a particular burden on the individual, who must engage in a constant "information management" effort: selectively disclosing and regulating information about their condition in order to mitigate the social impact of stigma and preserve daily relationships.

In the case of degenerative illnesses such as Alzheimer's, this theoretical model is particularly relevant. Although the disease may begin subtly or ambiguously, it progressively transforms the way individuals are perceived and treated both publicly and privately. As with other conditions (Lombi, 2022), the visibility of Alzheimer's changes over time. In its early stages, it may be hidden behind minor memory lapses or subtle behavioral changes; as the disease progresses, symptoms become more evident, and the individual may be perceived as "incompetent," "incomplete," or even as a "social burden" (Behuniak, 2011). This perception fuels a form of stigma that affects not only the person living with dementia but also their close network, especially family caregivers.

According to Link and Phelan (2001), stigma unfolds through five interrelated processes: labeling, stereotyping, separation, status loss, and discrimination, all of which operate within an asymmetrical power context. In the case of dementia, labeling is further complicated by the multiplicity of terms used in medical and social discourse (Alzheimer's, dementia, MCI, SCI), which contribute to confusion and to the broader medicalization of the condition (Schermer & Richard, 2019).

The stigma surrounding Alzheimer's has concrete implications. Many people delay seeking a diagnosis to avoid the social mark of the disease (Burgener et al., 2013; Stites et al., 2016). Caregivers, too, often hesitate to seek support due to fear of judgment or exclusion. This delay can impede access to

care, information, and coping strategies, exacerbating both isolation and emotional burden (Lopez et al., 2019). Moreover, stigma has ripple effects on disease management: individuals with dementia often withdraw from social life, while families limit public interactions out of fear of stigmatizing responses. Health institutions, in turn, may prioritize diagnostic and clinical aspects at the expense of person-centered approaches that address relational and emotional needs.

Several studies highlight that one of the most frequently reported emotions among family caregivers at the time of diagnosis is loneliness, experienced on multiple levels (Lopez et al., 2019). This begins with a rupture in personal identity: the caregiver, often a close family member, must renegotiate their role, gradually losing spaces of autonomy and self-definition. A second level of loneliness arises from social exclusion, reinforced by the stigma associated with Alzheimer's (Hung et al., 2021). Caregivers are often excluded from their own social networks due to others' discomfort in confronting the disease, which remains a collective taboo (Lopez et al., 2019).

Alzheimer's disease, therefore, transcends the biomedical dimension and emerges as a socially constructed condition, in which the diagnosis redefines the public identity of the person living with dementia. This redefinition is shaped by narratives that convey a sense of identity "void," a progressive dehumanization of the subject (Behuniak, 2011; Gerritsen et al., 2016). Phrases such as "no longer themselves" or "empty shells" reinforce a catastrophic view of dementia (Kontos et al., 2017; Zeilig, 2014), with detrimental effects on social acceptance and quality of life (Lee et al., 2020).

In this context, Tom Kitwood's foundational contribution is particularly significant. As the pioneer of the person-centered approach to dementia (1997), Kitwood critically challenged the reduction of the individual to a purely biological object, proposing a paradigm shift: dementia is not only a neurodegenerative condition, but an interpersonal and relational one. His theory of "malignant social psychology" illustrates how institutional and cultural behaviors can undermine the dignity of people with dementia. Conversely, the person-centered model affirms the persistence of identity and the need for meaningful relationships, which is essential for counteracting stigma and restoring agency even in the advanced stages of the disease.

The catastrophic framing of dementia reinforces stigma, generating fear and shame (Stites et al., 2016; Velilla et al., 2022; Werner et al., 2019). Misinformation, often amplified by media narratives, worsens this effect, while recent research suggests that increased public awareness can foster more positive perceptions (Farina et al., 2024; Rodriguez, 2013).

Stigma by association also affects caregivers, who are often perceived as incompetent or socially marginal. This "double stigma" contributes to shame

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

and social withdrawal, with negative consequences for mental health (Maxfield & Greenberg, 2021; Navab et al., 2012). In many cultural contexts, asking for external help is viewed as a loss of dignity (Baghirathan et al., 2018), compounding caregivers' sense of solitude.

Addressing these dynamics requires a profound cultural shift. Promoting alternative narratives that highlight residual abilities and the continuity of identity may support greater social inclusion and a more empathetic care culture (Cheston et al., 2018; Van Wijngaarden et al., 2019). Educational, experiential, and artistic interventions have proven effective in reducing stigma (Bienvenu & Hanna, 2017; Twardzicki, 2008). Among these, Burns and colleagues (2018) explored the use of theater as an educational tool to reduce stigma and enhance public understanding of Alzheimer's and dementia. Their performance *Seven Stages, Seven Stories*, featuring actors with personal experience of dementia, fostered greater audience openness in discussing the illness and valuing creative arts as a vehicle for awareness. The results indicate a positive shift in audience perception and emotional engagement, supporting the transformative potential of theater to challenge stereotypes and build empathy. The authors advocate for integrating such approaches into broader educational initiatives aimed at producing lasting changes in public attitudes toward dementia.

Stigma reduction also requires structural changes: policies that protect privacy and rights, healthcare professional training, and the inclusion of people with dementia in community settings (Bacsu et al., 2022). The broader challenge is to shift from a purely pathological view of dementia to a relational and social perspective, one in which the individual, despite vulnerability, continues to be recognized as a person of value (Costa, 2020). Only through cultural transformation, supported by inclusive public policies and alternative social narratives, will it be possible to meaningfully reduce the stigma surrounding Alzheimer's disease and foster a more equitable and compassionate society. However, as Goffman (1963) observed, processes of destigmatization often develop within "circles of the wise", individuals already sensitized or personally involved in the issue. This suggests that cultural initiatives such as festivals may generate inclusive and empathetic contexts whose transformative impact remains largely internal, unless specific strategies are developed to extend these practices and meanings into the wider social sphere.

## ***2.2. Beyond entertainment: Festivals as spaces of care***

Festivals represent collective ritual moments in which a community gathers to celebrate shared values, identities, and symbols. As Richards (2017) highlights, they are forms of public aggregation centered on topics of common

interest and capable of reinforcing a sense of belonging. According to Van Winkle and Woosnam (2013), festivals activate social cohesion dynamics by creating collective mental states, a phenomenon Émile Durkheim (2005 [1912]) referred to as “collective effervescence,” essential to the reproduction and legitimization of communal bonds.

Following Victor Turner’s (1982) theoretical framework, festivals can be understood as a form of *communitas*—a liminal condition in which social hierarchies are temporarily suspended, encouraging egalitarian and authentic interaction among participants. Contemporary studies reinforce this interpretation, demonstrating that cultural festivals are not merely recreational events but contexts that generate psychological, relational, and social well-being (Gorchakova & Hyde, 2022). They promote intergenerational dialogue (Wood et al., 2018), foster community integration (Quinn, 2019), and act as catalysts for collective resilience (Derrett, 2018).

Festivals function as polysemic cultural tools that, through their ritual dimension and emotionally shared experience, serve as potential agents of change at individual, community, and societal levels (Alonzo & Rossetti, 2023). In addition to emotional and relational well-being, participation in festivals may generate benefits in terms of knowledge acquisition and skill development, both of which are linked to psychological and mental well-being (Rossetti, 2021). Some studies have also focused on spiritual well-being, analyzing the festival experience as a sacred or devotional encounter (Mackay, 2014).

Moreover, festivals play a strategic role in redefining the very concept of culture, contributing to the breakdown of traditional distinctions between high and popular culture. Numerous scholars have emphasized the social value of festivals as spaces where new identities emerge and community-based socialization occurs (Small et al., 2005; Richards, 2017). From this perspective, festivals can also respond to phenomena of marginalization. Hassanli et al. (2020) point out that such events may serve as tools to mitigate the negative effects of social exclusion, promoting the inclusion of vulnerable groups by activating practices of cultural welfare, a model of well-being that promotes health, inclusion, and social cohesion through arts and culture (Alonzo & Rossetti, 2023). In this sense, as Dragan Klaić (2002) affirms, “building a relationship also means sharing responsibility and making local civic group members active participants rather than mere consumers” (p. 34).

According to Allport’s (1954) Contact Hypothesis, opportunities for social interaction, such as festivals and public events, offer significant means to counteract the stigma associated with conditions such as mental illness, disabilities, and chronic diseases, a point supported by several recent studies (Quinn et al., 2011; Reigada et al., 2019). In particular, inclusive celebrations, such as global awareness days dedicated to health and illness, create spaces in

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

which personal testimonies can be shared, awareness can be promoted, and marginalized experiences can be normalized.

These dedicated awareness days play a crucial role in informing public opinion, disseminating scientific knowledge, and supporting those directly or indirectly affected by the conditions, including caregivers and families. Through activities such as conferences, information campaigns, and community events, these initiatives help stimulate dialogue, increase understanding of patient needs, and mobilize resources for research and social support.

At the same time, part of the literature invites caution regarding the transformative potential of festivals. Some authors (Quinn, 2019; Richards, 2017; Derrett, 2018) suggest that, while such events may foster valuable moments of participation and empathy, their social effects often remain temporary or confined to already engaged communities, raising questions about the durability and breadth of their impact.

A growing body of research, however, highlights the effectiveness of such initiatives in enhancing social cohesion and facilitating access to diagnosis and treatment. For example, Butler et al. (2018) demonstrate that awareness campaigns reduce misinformation and promote proactive health behaviors. Similarly, Brown et al. (2020) emphasizes the importance of integrating narrative, artistic, and musical elements into awareness-raising events, which make the message more empathic, accessible, and memorable.

In this context, festivals may be interpreted as genuine community rituals capable of generating spaces of visibility, inclusion, and shared reflection. By bringing together individuals from diverse social, cultural, and ethnic backgrounds, such events foster empathy and solidarity, transforming the individual experience of illness into a collective narrative. Furthermore, as noted by Derrett (2018), these occasions help build collective resilience by strengthening communal ties and promoting a shared sense of responsibility. An emblematic example is the Festival Internacional de Cortometrajes y Arte sobre Enfermedades (FICAE), a film and art event held annually in Spain, analyzed by Reigada et al. (2019). Through screenings of short films followed by public discussions, the festival has facilitated more empathic and critical understanding of complex issues such as suffering, dementia, and death. Exposure to audiovisual narratives has stimulated collective reflection, helping to dismantle stigma and symbolically regenerate the identities of both those living with illness and their caregivers. In this sense, the festival is configured not merely as a cultural event, but as a transformative space capable of generating dialogue, social awareness, and inclusion.

### 3. Representing illness through festivity: The case of Alzheimer fest in Italy

The juxtaposition of the terms “festival” and “Alzheimer’s” may, at first glance, appear paradoxical or even inappropriate. Yet it is precisely this apparent incongruity that constitutes the conceptual core of the challenge undertaken by the creators of Alzheimer Fest: transforming a cultural event into a symbolic space that disrupts the social stigma surrounding the disease. The explicit aim of the festival is to contribute to the destigmatization of Alzheimer’s by promoting an inclusive narrative of the illness - one that restores dignity to those affected and acknowledges the role of caregivers, celebrating the continuity of life through an atmosphere of festivity, empathy, and shared participation.

Alzheimer Fest was founded in 2017, emerging from the fusion of “Alzheimer”, the well-known neurodegenerative condition, and “Fest,” an intentional reference to the Bavarian Oktoberfest. The goal was to symbolically merge two contrasting dimensions: the anxiety often associated with the diagnosis (Kontos et al., 2017) and the convivial atmosphere of a festival, creating a semantic short-circuit capable of challenging entrenched social prejudices<sup>2</sup>.

Alzheimer Fest is part of the vibrant landscape of Italian festivals, which includes over 2,300 events across the country, more than 500 of which are devoted to cultural engagement. A growing number of these festivals focus on themes of care and illness, aiming to bring the public closer to new narratives that transcend the traditional boundaries of medical pathologies.<sup>3</sup>

Promoted by journalist Michele Farina (*Corriere della Sera*) and Professor Marco Trabucchi (Full Professor at the University of Rome “Tor Vergata” and President of the Italian Association of Psychogeriatrics), the festival was first held in Gavirate (VA), in collaboration with the local association Rughe. From its second edition onward, Alzheimer Fest adopted a traveling format, relocating to different Italian cities with the goal of disseminating a widespread culture of inclusion. After the inaugural event in Gavirate (2017), the

---

<sup>2</sup> In this regard, special attention should be given to the festival’s logo, created in 2017 by the Florentine artist Clet Abraham. Notably, the word “Alzheimer” in the logo is missing the letter “H.” As recounted by Farina on the festival’s official website: “Clet deliberately left out the ‘H’ in the word Alzheimer. An artist’s idea. You may like it or not, but in any case, it is not meant to be a slight to science or a sign of disrespect toward those facing dementia. Alzheimer’s is no joke. Or is it?” For further information, see: <https://www.alzheimerfest.it/2025/04/28/perche-manca-la-h-nel-logo/>

<sup>3</sup> For further information, see: <https://trovafestival.it/>

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

subsequent editions took place in Levico Terme (TN, 2018) and Treviso (2019). Despite the challenges posed by the COVID-19 pandemic, the festival continued in 2020 in Cesenatico, which also hosted the event in 2021.

Since 2022, the initiative has adopted a more structured format, following a multi-date model primarily concentrated in the months of September and October, coinciding with World Alzheimer's Day (21 September). In 2024, the festival included as many as eight stops: 7–8 September in Gavirate and Senigallia, 14–15 September in Levico Terme, 21–22 September in Melegnano, 28–29 September in Bologna, 4–5 October in Baggiovara (MO), 6 October in Giovinazzo (BA), and 18–19 October in Lamezia Terme (CZ). The selection of locations is particularly significant, with events held primarily in public spaces such as municipal libraries, squares, cultural sites, parks, and theaters. Notably, this edition featured, for the first time, a festival stop within a hospital setting. The organization of each stop is managed by the Alzheimer Fest Association in collaboration with local authorities, grassroots organizations, and public institutions. Each edition offers a rich and diversified program across multiple days, in both indoor and outdoor venues, with the aim of engaging the entire local community.

The cultural and educational program of Alzheimer Fest includes scientific and public-facing conferences, featuring neurologists, psychologists, researchers, educators, social workers, nurses, and other healthcare professionals. These forums address topics such as early diagnosis, pharmacological and non-pharmacological treatments, home and residential care models, patients' rights, caregiver support, and innovations in prevention and care.

Each edition of the festival is organized around a specific theme. The theme for the 2024 edition, "Emergency Response Ready," highlights both the urgent need for concrete solutions to the dementia crisis and the necessity to redesign emergency care settings to better accommodate the needs of people with dementia.

In addition to scientific and informational activities, the festival features a wide array of artistic and participatory initiatives. Theatrical performances are especially prominent, often exploring themes such as memory, identity, and the experience of illness. These performances may be produced by professional theatre companies or amateur groups, sometimes including people with dementia and their families. The program also includes live music, dance performances, and expressive or hands-on workshops aimed at a diverse audience that includes people with dementia, caregivers, and care professionals. Workshops range from painting and writing to cooking, gardening, and movement-based activities, with the goal of stimulating residual abilities, fostering social interaction, and encouraging accessible forms of personal

expression.

A dedicated space is also provided for public testimonies, where family members, former caregivers, or individuals living with cognitive decline share their experiences. These sessions, which are moderated and structured, serve both informative and participatory purposes.

The festival's cultural offerings are completed by photographic exhibitions and art installations inspired by themes such as memory, aging, and vulnerability. Finally, special emphasis is placed on dialogue among citizens, professionals, and institutions, with the aim of fostering a culture of welcome and active participation while combating the persistent social stigma surrounding Alzheimer's disease.

#### **4. Methodology**

To analyse the case study of Alzheimer Fest and the tools implemented to counteract stigma and reshape the social representations of Alzheimer's disease, with potential effects extending beyond the duration of the event itself (Getz, 2007), an ethnographic approach was adopted. The methodological framework was entirely qualitative, grounded in multiple data collection strategies: desk analysis, direct field observation, and interviews and conversations conducted before, during, and after the festival (Kennell & Sitz, 2010). The document analysis included an examination of online sources related to past editions of the festival, covering information on its organizational structure, programming, history, and key figures involved.

The adopted approach drew inspiration from Falzon's (2001) definition of ethnography as a situated combination of fieldwork techniques, including note-taking, audio and video recordings, interviews, analysis of "indigenous" literature, and observation, anchored in the ideal of participant observation. This research is grounded in an ethnographic perspective informed by studies conducted in both cultural festival contexts and the healthcare field (Chatwin et al., 2022).

Fieldwork was conducted between July and October 2024, with a more intensive phase of on-site observation taking place between September and October. The research followed the festival through its various stops in Gavirate (VA), Melegnano (MI), Bologna (BO), Baggiovara (MO), and Lamezia Terme (CZ), in order to gain direct experience of the event, its operational dynamics, and its presence and reception in the local territories it traversed.

#### **4.1. Observation**

Observation was articulated through two complementary modalities. The first involved participation as observers, with the aim of attending workshops, performances, and events, monitoring the organisation, and capturing the overall atmosphere of the festival, while collecting testimonies, impressions, and comments from participants and audience members. The second modality consisted of participatory observation through active involvement as a volunteer, collaborating with the organizers in the implementation of the event (Holy, 1984). This position enabled close engagement with organizational and relational dynamics, allowing for the monitoring of interactions between attendees, volunteers, and staff, as well as the identification of critical issues, strengths, and potential spaces for the development of new practices.

The researcher's stance was guided by a reflexive and situated engagement, consistent with the principles of participatory ethnography: not a neutral and detached observer, but a subject entering into a relationship with the field, sharing its rhythms and spaces, and adopting a dialogical position attentive to the co-constructed meanings negotiated with social actors. This approach allowed for the analysis not only of the explicit content of practices and discourses but also of their implicit meanings, emotional dimensions, and symbolic tensions embedded in the festival experience.

The observational framework adopted draws on Giddens' (1984) structuration theory, which offers a dual vision of social reality in which structure and agency are not separate entities but mutually constitutive. According to this perspective, social practices are both the medium and the outcome of individual actions, always enacted within specific spatial and temporal contexts, and shaped by practical, embodied knowledge, what Giddens terms "practical consciousness", often unspoken by the actors themselves. In this light, ethnographic research is not limited to descriptive data collection but becomes a privileged tool for analyzing the processes through which practices are reproduced, modified, and imbued with meaning within systems of continuously negotiated rules and resources.

The observation of everyday interactions and organizational dynamics enables the positioning of individual and collective actions within a shared horizon of meaning that is defined in the course of social action itself (Giannini, 2020), in line with the premise of mutual constitution between agent and structure.

The entire participatory process was accompanied by the compilation of a reflective journal (field notes), aimed at documenting the field experience, the researcher's involvement, and their interpretative lens. Informal conversations were also conducted with audience members and volunteers during the festival.

These occasions provided unstructured data in the form of comments, discursive fragments, and opinions that enriched the ethnographic field notes.

#### 4.2. Interviews

Thirteen in-depth interviews were conducted, involving organisers, staff members, volunteers, and participants. The interview was chosen for its ability to elicit subjective experiences, personal narratives, and the symbolic meanings attributed to both the illness experience and participation in the festival-dimensions that are central to analyzing the processes of (de)constructing stigma. The interviews were carried out between June and November 2024, with durations ranging from 30 to 120 minutes, and provided a space for the emergence of reflections, anecdotes, and insights. Some interviews were audio-recorded, with informed consent, and later transcribed; others were documented through contemporaneous transcription and note-taking.

The selection criteria for interviewees were defined during the preliminary observation phase and calibrated according to the principle of heterogeneous stratification. Representation from each key category (organizers, volunteers, professionals, audience) was ensured, including individuals from both professional and civil society spheres, who had engaged with the festival during at least one of its 2024 editions.

*Table 1. Socio-demographic overview of interviewees. All names have been anonymized. The table summarizes the participants' gender, age range, and primary role or relation to dementia to contextualize the excerpts cited in the analysis.*

Interviewee ID	Gender	Age range	Role/Relation to dementia
Interviewee_1	M	50–59	Organizer & former caregiver
Interviewee_2	M	70–79	Organizer & former caregiver
Interviewee_3	F	40–49	Audience & family caregiver
Interviewee_4	F	70–79	Organizer & health professional
Interviewee_5	F	60–69	Audience & family caregiver
Interviewee_6	M	70–79	Audience & family caregiver
Interviewee_7	F	70–79	Audience & family caregiver
Interviewee_8	F	70–79	Audience & family caregiver
Interviewee_9	M	50–59	Health professional & educator
Interviewee_10	F	30–39	Volunteer & cultural mediator
Interviewee_11	F	30–39	Volunteer & cultural mediator
Interviewee_12	F	40–49	Organizer & caregiver
Interviewee_13	M	60–69	Volunteer & health professional

The purpose of the interviews was to understand how the artistic and cultural practices promoted by the festival could have an impact on specific

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

local contexts and target groups. In addition to examining the organization and programming of the event, the research sought to investigate the processes and practices implemented by the festival to foster change, both culturally and socially (Brownnett, 2018). The interview guide explored two main axes: on the one hand, the relationship between the festival and the public communication of the illness; on the other hand, the potential for such an event to contribute to the destigmatisation of dementia.

Interview analysis was conducted through a qualitative content analysis approach, specifically thematic analysis (Braun & Clarke, 2006), which allowed for the recursive identification, organization, and interpretation of emerging themes within the textual material. The initial analytical framework was based on the interview guide, which had been developed in alignment with the research objectives and guided the first phase of coding.

## 5. Analysis of Results

### *5.1 The festival as a social space for destigmatisation and recognition*

The Alzheimer Fest constitutes a social and cultural laboratory that actively challenges stigmatizing representations of dementia. Far from being merely a celebratory or informational event, the festival creates a hybrid space in which individuals living with dementia, caregivers, health and social care professionals, and members of the public can engage in new, symbolically charged forms of interaction. In this sense, it operates as a cultural welfare device: a space where culture, understood as relationship, narrative, symbol, and shared experience, becomes an infrastructure of well-being, a driver of recognition, and a catalyst for social transformation.

*“It wasn’t an easy thing because it meant breaking, so to speak, a prejudice, and at the beginning I wasn’t entirely convinced either. But we took the plunge and, all things considered, the seed bore fruit, because then both we and XXXX continued in a significant way.” (interviewee\_2)*

The decentralized and adaptive structure of the festival fosters processes of social and cultural co-production that restore dignity and value to caregiving experiences, making them visible and collectively shared. Each stop is tailored to the specificities of the local context, co-constructing with local actors a participatory space in which the illness is addressed not merely as a clinical condition, but as a relational and communal experience. In this respect, the Alzheimer Fest is not simply an event, but a transformative context in which a

form of relational citizenship is affirmed: care, traditionally seen as a private matter, becomes a public practice, recognised and validated through rituals, narratives, everyday gestures, and collective actions.

*“Another colleague of mine invited me to the festival. She had joined earlier because of her mother, and after talking together, she encouraged me to attend so I could meet the people. I followed her advice, and I must say it truly bore fruit.”*  
(interviewee\_8)

Through performative (theatre, music, dance), aesthetic (art, photography), relational (workshops, public conversations), and affective (communal gatherings, informal rituals) practices, the Alzheimer Fest deconstructs the pathologizing narrative of dementia, refocusing attention on the person in their relational and symbolic wholeness. The presence of people with dementia not as objects of care but as active subjects and participants transforms the dominant caregiving framework, from medicalization to the co-production of meaning.

This reconfiguration is enabled by a set of practices that disrupt the existing symbolic order. The event is grounded in an aesthetic of reversal and contamination: irony, play, exaggeration, and anomaly become cognitive and affective tools to defuse the fear and silence surrounding Alzheimer’s disease. In this sense, the festival is not merely a showcase of best practices but a performative apparatus that generates new possibilities for social imagination, new ways of sensing and conceptualizing illness and care. It functions as a cultural device capable of reshaping the field of the possible. This dynamic was visible in several workshops and encounters where a new sense of normality emerged as the central focus of collective experience. During the *book cover workshop*, for instance, participants were invited to imagine and design the cover of “their own book” (the book of their life). Starting from an activity that many found enjoyable and familiar, they reflected on personal memories, invented titles, and shared stories that reconnected them with aspects of identity and creativity often overshadowed by the illness. Similarly, in concerts and dance sessions, caregivers and their relatives with dementia sang and moved together, blurring the boundaries between roles of assistance and vulnerability. These moments transformed care into a shared performative act, where bodily presence, rhythm, and playfulness generated a sense of mutual recognition and joy.

Through such practices, Alzheimer Fest translated the theoretical notion of an *aesthetic of reversal and contamination* into lived experience: irony, participation, and affect became everyday tools for redefining what counts as normality, thereby dismantling the silence and fear surrounding dementia.

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

*“Seven years ago, I was not yet part of the XXX group. I was in the midst of my full caregiver role, in the ‘let’s roll up our sleeves’ phase, and I heard XXX say: ‘Maybe in September we’ll organise a festival called Alzheimer Fest.’ We were in the regular support groups for family members, and to me it was a breath of fresh air—how wonderful, we’re doing a festival. I was in the middle of my caregiving chaos, so for me it was: ‘Thank goodness for this festival.’ I took part as a volunteer.” (interviewee\_5)*

*“Luckily there is the Alzheimer Fest, because through this event I was able to discover the reality of Gairate, the people who work there, the volunteers. [...] From the start we felt welcomed, because there is an attention to the person, to certain details, that truly amazed me. Being able to share this illness with others is a great help, because we didn’t feel alone or lost.” (interviewee\_7)*

In analytical terms, the deconstruction of the pathologizing narrative observed at Alzheimer Fest unfolds through three intertwined mechanisms. First, the event *symbolically displaces* dementia from the medical domain to the cultural and communal sphere: by merging illness with festivity, it reframes Alzheimer’s not as a deficit but as a shared human condition, open to empathy and creativity. Second, through participatory and aesthetic practices (e.g. theatre, music, collective meals, workshops) people with dementia appear as *agents* rather than patients, thus inverting the conventional subject/object hierarchy of care. Third, the festival promotes *narrative reframing* by allowing new public stories to circulate: testimonies, humor, and play dismantle stereotypes of loss and incapacity, replacing them with narratives of continuity, reciprocity, and presence.

These mechanisms, articulated through embodied and symbolic action rather than through discourse alone, enable the festival to “refocus attention on the person in their relational and symbolic wholeness,” as mentioned earlier. They also reveal that deconstruction does not occur automatically through the festival’s existence, but through the situated interactions, emotions, and representations generated in its performative spaces.

### ***5.2. The festival as a cultural device for rewriting the dementia imaginary***

One of the central features of the Alzheimer Fest is the multiplicity of languages employed to narrate and share the experience of dementia: not only words, but also bodies, images, gestures, and sounds. Verbal language, often hindered by the illness itself, gives way to alternative forms of expression that

facilitate subjective communication, emotional connection, and relational reconnection. In this context, the festival operates as a cultural ecosystem that values unconventional modes of communication, capable of giving voice to those who, in everyday life, are often confined to silence.

The encounter between caregivers, family members, and people living with dementia thus does not occur within the conventional framework of the helping relationship. Instead, it unfolds in a horizontal, playful, and symbolic dimension, allowing for a redefinition of power dynamics and implicit hierarchies within the care relationship. The act of dancing together, sharing a meal, or listening to music side by side temporarily suspends institutional roles and creates a more symmetrical relational economy. This constitutes a genuine process of restoring emotional and social citizenship to vulnerable individuals, who find within the space of the festival a place to be recognized beyond their diagnosis. Yet, this horizontality should not be idealized. The fieldwork also revealed that the encounters facilitated by the festival often involve participants already familiar with dementia or engaged in caregiving networks. As a result, these spaces of equality may risk reproducing, in an open setting, the same relational circles that exist within domestic or institutional contexts. While such dynamics undoubtedly foster emotional relief and mutual support, their transformative reach toward the broader public remains partial, since those most inclined to stigmatize the illness rarely take part in the event.

*“We talked about it with the group, which was initially a bit skeptical, but then everything took off—we set up this gamble because, in the end, we all believed in it, so we moved forward.” (Interviewee\_1)*

These processes are not merely events but transformative and situated practices that unfold over time. The festival thus functions as an accelerator of possibilities: it generates relationships that often extend beyond the temporal and spatial boundaries of the event itself, fostering networks of solidarity, unexpected alliances, and new visions of care.

*“It’s true, the word itself is frightening. I’ve noticed many people struggle with it. If it had been called something like ‘Festival of Memory’ or ‘Let’s Remember More’, it would have been different. But ‘Alzheimer’—I once wanted to bring my mother-in-law to the Alzheimer Fest, and my brother-in-law reacted: ‘What do you mean? You’re bringing her there, she’ll read the signs and feel bad.’” (Interviewee\_10)*

*“It’s not Alzheimer that is being celebrated—it’s the life behind the pathology [...] but the word Alzheimer represents a barrier. It’s a barrier because people don’t*

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

*want to confront this kind of issue. And it's not about it being a 'festival' per se, but rather: 'Why should I attend an Alzheimer festival?' We see this issue often. Who comes? Only people directly involved—professionals, caregivers, people with dementia who often don't even know where they are going." (Interviewee\_13)*

In this sense, Alzheimer Fest operates as a counter-hegemonic space, capable of redrawing the boundaries of illness, between care and culture, between vulnerability and potential. It constitutes a genuine collective counter-narrative, one that overturns the dominant paradigm by proposing an aesthetic of encounter and relationship, rather than a technical, performance-based model of care. As one interviewee recounted:

*"I believe there is an enormous need for dissemination because, unfortunately, the topic is either discussed in a highly technical way—which is incomprehensible for non-medical professionals—or in a trivializing manner. Nowadays, anyone can speak on the subject, make videos, give advice on YouTube or in newspapers, and this often leads to dementia being shockingly trivialized." (Interviewee\_9)*

The initiative *Un nodo in corsia* (A Knot in the Ward), carried out within a hospital setting, emblemizes this attempt to contaminate clinical environments with symbolic and relational practices of welcome. Through simple yet meaningful gestures, a symbolic object, a shared narrative, a space for listening, the project aims to reconfigure the relationship among healthcare professionals, people with cognitive decline, and their families, introducing elements of empathy and reciprocity. The illness is neither denied nor sugar-coated but recontextualized: from a medical condition to be managed functionally, to a social and cultural experience that challenges the collective. In this way, care becomes a social and symbolic act rooted in shared meanings and relationships, and dementia becomes an opportunity to rethink our categories of normality, value, and participation.

***5.3. The festival as a laboratory of engagement, advocacy, and vulnerable citizenship***

One of the key findings emerging from field observation concerns the processual, rather than episodic, nature of the Alzheimer Fest. The event does not exhaust its transformative potential within the temporal limits of the festival itself; rather, it constitutes part of a broader process of meaning-making, social connection, and the production of new imaginaries. The festival is deeply embedded in local contexts, intersecting with both local and national networks,

and fostering over time the emergence of widespread practices of collective care.

From this perspective, Alzheimer Fest can be understood as an embodied cultural policy, one that intervenes in the symbolic and affective spheres in order to redefine public priorities. Its objective is not merely to raise awareness, but to challenge and transform the normative and value systems that underpin existing practices of exclusion, silencing, and the medicalization of suffering. The festival acts as a form of cultural advocacy, where the right to care is interwoven with the right to narrate, to experience beauty, and to participate fully in public life.

*"I believe that the event can serve as a channel to bring people with dementia and their families closer to a context that is not solely medical. The goal is not so much for people to attend the Alzheimer Fest, but rather that through the Alzheimer Fest, those who are directly affected might come to perceive that there is something beyond the medical clinic—which may offer some medication, some advice, or something else, but which remains profoundly insufficient as a true form of care for this type of disease. So I believe the point is not how to attract people to these events, but rather how to develop the potential of these events to connect people with other local realities—mutual support groups, associations, cultural or educational initiatives—that often provide families and people with dementia with support and, one could say, a bit of breathing space." (interviewee\_9)*

The concept of cultural welfare finds full expression in this context: Alzheimer Fest generates social and relational well-being through cultural practices, while simultaneously challenging institutions to support and expand such spaces of innovation. In a society marked by deep inequalities and the marginalization of vulnerability, the festival demonstrates how art, storytelling, interpersonal relationships, and play can act as catalysts for a renewed vision of an inclusive community.

It is not merely about “providing care,” but about re-generating communities of meaning. Within the festival, care is not an individual act but a shared, distributed, and multifaceted practice that reconfigures the geography of health and citizenship. In this sense, Alzheimer Fest represents a concrete and radical form of cultural welfare: a public laboratory for experimenting with alternative visions of cohabitation, fragility, and dignity.

*"It was a challenge from the beginning, and Alzheimer Fest was born precisely so that people would start to understand that Alzheimer's is not only what people usually think, but so much more—because often it brings people together, allows them to share experiences that, when faced alone, become overwhelming or*

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

*panic-inducing.” (interviewee\_3)*

Through Alzheimer Fest, vulnerability, often treated as something to be hidden or overcome, is reclaimed as a shared public value, a source of new relational and political possibilities. The community it fosters is an inclusive one, open to difference and oriented toward hospitality rather than erasure or segregation. For this reason, the festival cannot be reduced to a mere cultural or recreational event: it constitutes a political practice of care, a collective performative act that transforms public space by giving visibility, voice, and value to lives that society tends to silence. It is here that the affective dimension of citizenship becomes manifest, not as abstract rights, but as a situated form of citizenship grounded in connection, shared memory, presence, and relationality.

*“We also see it as the creation of a community that embraces fragility in a broader sense, because fragility exists in all areas, not just among elderly people with illness. Alzheimer Fest was essentially a disruptive event, but it generated many things—it led to our workshops through a regional project, because at the beginning funding is necessary (and still is), and it triggered the will to become a Dementia Friendly Community. So many new initiatives emerged that had not previously existed in our area.” (interviewee\_3)*

In this sense, Alzheimer Fest operates as a semi-open social sphere: a protected yet visible environment where empathy is rehearsed and made public. The festival’s most promising potential lies in its capacity to project these micro-practices of inclusion beyond the festival boundaries, through media narratives, collaborations with schools, and municipal partnerships, gradually extending the social legitimacy of non-stigmatizing representations of dementia.

## 6. Conclusions

The ethnographic analysis conducted on the Alzheimer Fest highlights how cultural events, structured through participatory and symbolically dense forms, can activate processes of change in the social representations of dementia and the relational practices that surround it. Far from being merely a communicative or celebratory occasion, the festival takes shape as a complex cultural *dispositif* capable of influencing shared meanings, interpersonal relationships, and the social organization of care. However, it must also be recognized that the de-stigmatizing effects observed during the festival primarily occur within a self-selected community already sympathetic to the

cause. The real challenge lies in transforming these temporary “bubbles of empathy” into bridges toward the wider public sphere, where stigma persists most strongly. Strengthening the connections between festival practices, local institutions, and media discourse could represent a crucial step in amplifying the festival’s capacity for social change.

The practices observed in the context of the festival, artistic performances, convivial moments, participatory workshops, storytelling spaces, serve as tools through which the public image of the disease is re-elaborated, along with the roles assigned to those involved, primarily people living with dementia and their caregivers. These practices do not produce direct or immediate effects at the institutional level but rather generate forms of social learning that shape individual dispositions, relational reciprocity, and the interpretive frameworks through which dementia is perceived and experienced.

In this sense, Alzheimer Fest can be interpreted as an operational example of cultural welfare: a model of intervention that employs the tools of culture, understood broadly as a set of expressive, symbolic, and relational practices, to promote well-being, inclusion, and citizenship. This approach does not replace traditional social and health services but complements them, providing a parallel sphere in which affectivity, communication, and participation are recognized and enhanced. As highlighted by several interviewees, the awareness of this deconstructive process is not always explicit among participants, yet it becomes tangible through embodied interactions and the emotional re-signification of the illness experience.

What emerges, in particular, is the processual and generative dimension of these practices: they do not end with the event itself but extend beyond it, embedding themselves in relational trajectories that contribute to the formation of more articulated social networks, the circulation of informal knowledge, and the redefinition of roles within the care system. In this way, the festival assumes a transformative value, catalyzing forms of mutual recognition and agency for individuals who, in ordinary contexts, frequently experience invisibility and marginalization.

From an analytical standpoint, the results of this study invite us to consider the potential of cultural policies as integrative tools alongside social and health policies, particularly in domains such as dementia care, where the symbolic and relational burden of illness is considerable. However, the valorization of cultural and participatory practices as instruments of welfare requires institutional recognition and a systemic vision capable of incorporating these initiatives into public strategies aimed at health, social cohesion, and inclusion.

Ultimately, the case of Alzheimer Fest suggests that it is possible to activate spaces of social change through situated cultural and relational practices.

It is also important to acknowledge that several scholars have expressed

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

skepticism toward the transformative capacity of cultural festivals, particularly regarding their long-term social impact. As noted by Quinn (2019) and Richards (2017), festivals often generate temporary communities of affect that may not translate into structural social change once the event ends. Similarly, Derrett (2018) warns that the celebratory nature of festivals can obscure existing inequalities and reproduce symbolic hierarchies rather than dismantle them. From this perspective, Alzheimer Fest can be seen as a “liminal” rather than revolutionary space, an experimental context that opens possibilities for change but whose outcomes depend on broader institutional and cultural conditions. Recognizing these critiques allows for a more nuanced understanding of both the potential and the limits of cultural events as instruments of destigmatization.

These practices do not replace the structural dimension of welfare, but rather complement and expand it, contributing to the construction of a care ecosystem that is more attentive to symbolic dimensions, subjectivity, and the quality of relationships.

## **7. Limitations and further researches**

Although the qualitative approach adopted allowed for an in-depth and nuanced exploration of subjective experiences and relational dynamics, this study presents several methodological and analytical limitations. Firstly, the sample of interviewees, although diverse, was primarily composed of individuals already actively involved in the festival or affiliated with associative networks, thereby limiting access to more marginal or critical perspectives. Moreover, field observations were restricted to a limited number of festival locations, which hindered the possibility of a systematic comparison between the different local implementations of the event.

Another notable limitation concerns the partial absence of the direct voices of people living with dementia, whose representation is often mediated by caregivers or professionals. This raises ethical and methodological questions regarding the possibility of involving individuals with dementia more directly and respectfully in research processes.

Finally, the analysis focused predominantly on the symbolic and relational dimensions of the festival, without conducting a systematic assessment of its tangible and long-term impacts on the local communities. Future research could address these aspects to evaluate the actual capacity of Alzheimer Fest to generate structured, as well as experiential, forms of social change.

## References

- Allport, G. W. (1954). *The nature of prejudice*. Addison-Wesley.
- Alonzo, G., & Rossetti, G. (2023). Festivals as instruments of cultural welfare: A theoretical reflection. *Welfare e Ergonomia*, 1(2023), 25–38.
- Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., & Currie, K. (2018). A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. *Dementia*, 19(5), 1672–1691.
- Bacsu, J.-D., Johnson, S., O'Connell, M. E., Vider, M., Muhajarine, N., Hackett, P., Jeffery, B., Novik, N., & McIntosh, T. (2022). Stigma reduction interventions of dementia: A scoping review. *Canadian Journal on Aging / La Revue canadienne du vieillissement*, 41(2), 203–213.
- Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing & Society*, 31, 70–92.
- Bianchetti, A., & Trabucchi, M. (2010). *Alzheimer*. Bologna: Il Mulino.
- Bienvenu, B., & Hanna, G. (2017). Arts participation: Counterbalancing forces to the social stigma of a dementia diagnosis. *AMA Journal of Ethics*, 19(7), 704–712.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brown, T., Smith, R., & Lee, C. (2020). Building awareness through celebration: The societal impact of health-related events. *Health Promotion International*.
- Brownett, T. (2018). Social capital and participation: The role of community arts festivals for generating well-being. *Journal of Applied Arts and Health*, 9(1), 71–84.
- Burgener, S., Buckwalter, K., Perkhounkova, Y., & Liu, M. (2013). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia*, 14(5), 609–632.
- Burns, N. C., Watts, A., Perales, J., Montgomery, R. N., Morris, J. K., Mahnken, J. D., Lowther, J., & Vidoni, E. D. (2018). The impact of creative arts in Alzheimer's disease and dementia public health education. *Journal of Alzheimer's Disease*, 63(2), 457–463.
- Butler, R., Kane, P., & Olshansky, E. (2018). Public awareness days: Analyzing their role in health promotion. *Journal of Health Communication*.
- Chatwin, J., Ludwin, K., & Latham, I. (2022). Combining ethnography and conversation analysis to explore interaction in dementia care settings. *Health Expectations*, 25, 2306–2313.
- Cheston, R., Jones, K., & Gilliard, J. (2018). Communication strategies for dementia: Supporting emotional well-being. *Dementia*.
- Costa, G. (2020). Vulnerabilità e fragilità in sanità pubblica, nelle politiche e nei

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance

Giulia Alonzo

- metodi di studio. *Epidemiol Prev*, 44(5-6), 14–17.
- Derrett, R. (2018). How festivals build resilient communities. *Event Management*.
- Durkheim, E. (2005). *Le forme elementari della vita religiosa* [1912]. Meltemi.
- Falzon, M. A. (2001). *Multi-sited ethnography: Theory, praxis and locality in contemporary research*. Ashgate.
- Farina, N., Hassan, E., Theresia, I., Fitri, F., Suswanti, I., Sani, T., Evans-Lacko, S., Banerjee, S., & Turana, Y. (2024). Awareness, attitudes, and beliefs of dementia in Indonesia. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 16(2).
- Getz, D. (2007). *Event Studies. Theory, research and policy for planned events*. Oxford: Elsevier.
- Gerritsen, D. L., Oyeboode, J., & Gove, D. (2016). Ethical implications of the perception and portrayal of dementia. *Dementia*, 17(5), 596–608.
- Giannini, L. (2020). “Siamo tutti volontari”. Etnografia di una Festa de l'Unità, tra retoriche e pratiche. FrancoAngeli.
- Giddens, A. (1984). *The constitution of society*. Polity Press.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall.
- Gorchakova, V., & Hyde, K. F. (2022). The impact on well-being of experiences at cultural events. *Event Management*, 26(1), 89–106.
- Hassanli, N., Walters, T., & Friedmann, R. (2020). Can cultural festivals function as counterspaces for migrants and refugees? The case of the New Beginnings Festival in Sydney. *Leisure Studies*, 39, 165–180.
- Holy, L. (1984). Theory, methodology and the research process. In R. F. Ellen (Ed.), *Ethnographic research* (pp. 13–34). Academic Press.
- Hung, L., Hudson, A., Gregorio, M., Jackson, L., Mann, J., Horne, N., Berndt, A., Wallsworth, C., Wong, L., & Phinney, A. (2021). Creating dementia-friendly communities for social inclusion: A scoping review. *Gerontology & Geriatric Medicine*, 7.
- Italian Ministry of Health (2022). *Dati epidemiologici*. <https://www.salute.gov.it/portale/demenze>
- Kennell, J., & Sitz, R. (2010). Greening Bonnaroo: Exploring the rhetoric and reality of a sustainable festival through micro-ethnographic methods. In *Proceedings of the Global Events Congress IV* (pp. 14–16). Leeds, UK.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.
- Klaic, D. (2002). *Festivals: Challenges of growth, distinction, support base and internationalization*. Department of Culture of the Tartu City Government.
- Kontos, P., Miller, K. L., & Kontos, A. P. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, 39(2), 182–198.

- Lee, S., Hong, M., & Casado, B. (2020). Examining public stigma of Alzheimer's disease and its correlates among Korean Americans. *Dementia*, 20(3), 952–966.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385.
- Lombi, L. (2022). Oltre gli aspetti clinici: le implicazioni sociali della malattia di Parkinson. In F. Tosi (Ed.), *Home care design for Parkinson's disease* (pp. 29–38). FrancoAngeli.
- Lopez, R. P., Rose, K. M., Kenney, L., Sanborn, V., & Davis, J. D. (2019). Managing shame: A grounded theory of how stigma manifests in families living with dementia. *Journal of the American Psychiatric Nurses Association*, 26(2), 181–188.
- Mackay, K. (2014). Art as a connection to the divine in women's lives: Cultural wellbeing through creative process. *The International Journal of Social, Political and Community Agendas in the Arts*, 8, 1–16.
- Maxfield, M., & Greenberg, J. (2021). Anticipated stigma and dementia-related anxiety in middle-aged and older adults. *Geropsych*, 34(1), 13–22.
- Mecocci, P., Cherubini, A., & Senin, U. (2002). *Invecchiamento cerebrale*. Roma: Critical Medicine Publishing Editore.
- Navab, E., Negarandeh, R., Peyrovi, H., & Navab, P. (2012). Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneutic study. *Nursing and Health Sciences*, 15(2), 201–206.
- Quinn, B. (2019). Festivals, community, and identity in contemporary society. *Journal of Cultural Heritage Management and Sustainable Development*.
- Quinn, N., Shulman, A., Knifton, L., & Byrne, P. (2011). The impact of a national mental health arts and film festival on stigma and recovery. *Acta Psychiatrica Scandinavica*, 123(1), 71–81.
- Reigada, C., Martín-Utrilla, S., Pérez-Ros, P., Centeno, C., Sandgren, A., & Gómez-Baceiredo, B. (2019). Understanding illnesses through a film festival: An observational study. *Heliyon*, 5(8), e02196.
- Richards, G. (2017). From place branding to placemaking: The role of events. *International Journal of Event and Festival Management*, 8, 8–23.
- Rodriguez, J. (2013). Narrating dementia. *Qualitative Health Research*, 23(9), 1215–1227.
- Rossetti, G. (2021). The role of literary festival attendance in generating attendees' health and well-being. *International Journal of Event and Festival Management*, 12(3), 265–278.
- Schermer, M. H. N., & Richard, E. (2019). On the reconceptualization of Alzheimer's disease. *Bioethics*, 33(1), 138–145.
- Small, K., Edwards, D., & Sheridan, L. (2005). A flexible framework for evaluating the socio-cultural impacts of a (small) festival. *International Journal*

Festivals and Stigma in Dementia: An Ethnography of Alzheimer Fest as a  
Space of Social Resistance  
Giulia Alonzo

- of Event Management Research*, 1, 66–76.
- Stites, S., Johnson, R., Harkins, K., Sankar, P., Xie, D., & Karlawish, J. (2016). Identifiable characteristics and potentially malleable beliefs predict stigmatizing attributions toward persons with Alzheimer's disease dementia: Results of a survey of the U.S. general public. *Health Communication*, 33(3), 264–273.
- Tremolizzo, L., Ferrarese, C. (2008). Clinica delle demenze. *Giornale di gerontologia*, 56(S1), 34-39.
- Turner, V. (1982). *From ritual to theatre: The human seriousness of play*. Paj Publications.
- Twardzicki, M. (2008). Challenging stigma around mental illness and promoting social inclusion using the performing arts. *Journal of the Royal Society for the Promotion of Health*, 128(2), 68–72.
- van Wijngaarden, E., van der Wedden, H., & Henning, Z. (2019). Understanding Alzheimer's: Redefining communication practices. *Aging & Mental Health*.
- Van Winkle, C. M., & Woosnam, K. M. (2013). Sense of community and perceptions of festival social impacts. *International Journal of Event and Festival Management*, 5, 22–38.
- Velilla, L., Acosta-Baena, N., Allen, I., Lopera, F., & Kramer, J. (2022). Analysis of family stigma and socioeconomic factors impact among caregivers of patients with early- and late-onset Alzheimer's disease and frontotemporal dementia. *Scientific Reports*, 12(1).
- Werner, P., Shpigelman, C., & Turgeman, L. (2019). Family caregivers' and professionals' stigmatic experiences with persons with early-onset dementia: A qualitative study. *Scandinavian Journal of Caring Sciences*, 34(1), 52–61.
- WHO (2024). *Dementia*. <https://www.who.int/en/news-room/fact-sheets/detail/dementia>
- Wood, E., Jepson, A., & Stadler, R. (2018). Understanding the well-being potential of participatory arts events for the over 70s: A conceptual framework and research agenda. *Event Management*, 22, 1083–1101.
- Zeilig, H. (2014). Dementia as a cultural metaphor. *The Gerontologist*, 54(2), 258–267.