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An Art Exhibition on Creative Activities of Family Members of Persons with Dementia as an Effective Tool for Science Communication: A Qualitative Assessment Study

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ABSTRACT

Dementia poses a huge challenge – not only to the persons living with the condition but also to their family and friends. Recent research has demonstrated that engaging in creative activities can serve as a coping mechanism to deal with the dementia of a loved one. An art exhibition was created to communicate this insight to a broader audience. As indicated by interviews with exhibitors and visitors as well as an analysis of notes that visitors left in the exhibition, the exhibition helped generating important knowledge regarding the usefulness of creative activities, opened new perspectives on dementia, and provided a platform for exchange and solidarity that inspired individuals to think and behave differently. In sum, this suggests that arts-based exhibitions can be a powerful tool for health communication and science communication and for broadening the societal discourse in the context of dementia.


Dementia poses a huge societal problem: As estimated by the World Health Organization (WHO, 2023), currently 55 million people live with dementia worldwide – a number that is rising at a rate of about 10 million per year. To date, there are neither interventions that prevent dementia (cf. Hafdi et al., 2021) nor pharmacological treatments that could cure the disease (cf. Lao et al., 2019). In recent years, scholars have attempted to view dementia through a disability lens (Shakespeare et al., 2019; Thomas & Milligan, 2018), emphasizing that dementia is not merely a medical condition but often goes hand in hand with social barriers and experiences of exclusion. The radical changes that come with dementia do not only affect the persons living with dementia, but also their family and friends (e.g., Bom et al., 2019; Cross et al., 2018). One established way of coping with the dementia of a loved one is the use of creative activities (for a review, see Irons et al., 2020). Usually, the effects of engaging in creative activities are investigated in the context of standardized arts-based interventions offered by a trained professional. A recent interview study conducted by the first author of the present study (Hutmacher & Schouwink, 2022) showed, however, that family members of persons with dementia also benefit from engaging in creative activities outside of standardized interventions, that is, from performing creative practices that are naturally embedded in their everyday lives. To share this insight with a broader audience and to create a platform for illuminating the lived realities of family members of persons with dementia, we organized an art exhibition based on artworks generated by the participants from the original interview study. The present investigation assesses the communicative potential and transformative power of this art exhibition, based on interviews

with exhibitors and visitors as well as an analysis of notes that visitors left in the exhibition. Before giving a detailed description of the exhibition, we first turn to the theoretical background that provided the starting point for our research.

Creative activities as a coping mechanism for family members of persons with dementia

The dementia of a loved one leads to fundamental transformations of established interpersonal relations and social roles, driven by the changes of communication and the perceived loss of the person (Albinsson & Strang, 2003; Clemmensen et al., 2019; Hutmacher, 2021; Rudd et al., 1999). In other words, the dementia of a loved one can make it necessary to renegotiate roles within the family system to be able to integrate the new situation and the new responsibilities into one's own identity (Cooper, 2021; Miller-Ott et al., 2022). This may include adapting strategies for communicating love and affection as well as exploring new ways for continuing to have intimate conversations or for sharing daily activities (Cooper et al., 2022; see also Hoppe, 2022). These adaptation processes are often complicated by the fact that dementia is still surrounded by negative stereotypes and fears that lead to stigmatization and medicalization (Low & Purwaningrum, 2020; Rosato et al., 2019). Against this background, researchers and practitioners have developed a wide range of psychosocial interventions for caregivers and family members of persons with dementia, including but not limited to educational interventions, support groups, and psychotherapy (for an overview, see Gitlin et al., 2015; Jackson & Browne, 2017). Indeed, support seeking and health information seeking can contribute to

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reducing caregiver burden and to increasing caregiver well-being (Mason et al., 2022; Schlag & Vangelisti, 2024).

Among the different interventions, arts-based interventions have received considerable interest in recent years (for a review, see Irons et al., 2020; see also Cameron et al., 2013), with the belief that creative activities executed by caregivers can serve as a means for adapting to the new situation and its challenges. This heightened interest in arts-based interventions in the context of dementia coincides with the heightened interest in arts-based research in general, pointing to the potential of creativity and the arts to transcend barriers, to open up spaces for communication, to create knowledge, and to increase overall health and well-being (Coemans & Hannes, 2017; Fancourt & Finn, 2019; Fraser & Sayah, 2011; Golden et al., 2024). While the creative activities used during arts-based interventions in the context of dementia vary greatly and include, for instance, music, art-making, dancing, and poetry writing, the effects of these arts-based interventions seem to be somewhat similar: Creative activities are usually perceived as positive and enjoyable activities that lead to relaxation and reduced stress. However, the effects of creative activities extend beyond such an immediate, *experiential level* in the sense that they can have various cognitive and emotional as well as behavioral and interactional effects. On a *cognitive level*, creative activities may change assumptions about dementia or one's role as a caregiver but also help to construct meaning in difficult times. On an *emotional level*, creative activities can have cathartic and mood-enhancing effects. In addition, engaging in creative activities may ultimately change how individuals behave in their daily lives (*behavioral level*) and how they interact with others, such as the person with dementia or other people from their personal environment (*interactional level*; see Irons et al., 2020).

Our recent interview study provided evidence that these positive effects can also be achieved by engaging in creative activities outside standardized arts-based interventions (Hutmacher & Schouwink, 2022). This suggests that family members of persons with dementia do not necessarily have to participate in specifically designed interventions but that it may suffice to pursue a creative activity in daily life. As these results are not only relevant for the scientific community but also for the public, and in particular for family members of people with dementia who might be looking for coping mechanisms that they can integrate into their daily lives, we thought about ways of communicating our research findings to the public. Given that the creative activities of the participants had resulted in the production of specific pieces of art, presenting these pieces in an exhibition and embedding them in the larger context of our research was an obvious choice. To better understand this choice, we want to situate our project within in the broader context of research on art exhibitions in the realm of health communication and science communication, as well as research on the nexus of art exhibitions and dementia.

(Art) Exhibitions as an effective tool of health communication and science communication

Health communication refers to all kinds of health-related communication, including everyday communication (du Pre

& Overton, 2024). One important aim of health communication in professional settings is fostering and improving health and well-being (Rimal & Lapinski, 2009). Among other practices, this is achieved through science communication, that is, through translating findings from academic research to a broader, non-expert audience, often with the goal to change individuals' knowledge structures, attitudes, and behaviors (T. W. Burns et al., 2003). Importantly, science communication is not necessarily unidirectional but can also involve dialogue and joint deliberation between researchers and the public (Gastil, 2017). Alongside other formats like popular science books or programs on television, exhibitions are used for science communication directed toward the public since many years (Liebert, 2020), as they offer a rich informal learning environment (Schwan et al., 2014). Of course, exhibitions can be conceptualized in many ways. However, current research on science communication does not only emphasize the importance of pictures and visualizations in general (Leßmöllmann, 2020), but also the potential of using the visual arts for science communication purposes in particular (for an overview, see Potts & Helyer, 2022). The hopes associated with science-art cooperations are summarized by Richardson (2002, p. 887): "Science is one lens, creative arts another; we see more deeply using two lenses." However, what exactly does that mean – and which positive effects can be expected from using the arts to communicate research findings that differ from the effects of more traditional forms of science communication (for an overview, see Lesen et al., 2016; see also Roosen et al., 2018)?

As with other means of science communication, the ultimate goal of relying on the arts usually is *reaching wider audiences*, that is, audiences that one may not be able to reach through publishing an article in a peer-reviewed journal (Fraaije et al., 2022, Nature Editorial, 2021). Furthermore, the arts particularly address the *affective dimensions*, that is, that they touch people's emotions who are confronted with the piece of art, leading the discourse in directions that go beyond mere cognitive and rational arguments (Nature Editorial, 2021). This goes hand in hand with the idea that the arts can *foster the understanding of complex findings or concepts* by providing an experience that potentially involves all senses (Falk & Dierking, 2000) and that is more accessible for the viewer than a mere presentation of facts (Bartlett, 2015). In addition, the arts have the ability to *encourage alternative ways of thinking and individual reflection*, which may ultimately lead to the inclusion of new perspectives into mainstream discourse or the shifting of social norms (Fraaije et al., 2022). This implies that engaging with the arts or with the content of an exhibition can lead to *behavioral changes* or at least a personal response to the thoughts and ideas expressed in certain pieces of art (Evans, 2014).

Research on dementia in the context of creativity and art exhibitions

Creativity and the arts inform many practices within the context of dementia (Siette et al., 2023). The use of creative techniques and approaches can not only help to break stereotypes and adjust problematic care practices but also make

interactions with persons with dementia more meaningful (Basting, 2009, 2020; Viola, 2021; see also Jonas-Simpson et al., 2022). Moreover, persons with dementia clearly need not be and should not be excluded from the research process (Shannon et al., 2021); they should tell their stories in their own voices (for examples of personal accounts of living with dementia, see, Snyder, 2009; Taylor, 2007).

However, relatively little research connects creativity and dementia in the context of art exhibitions: One study (Bartlett, 2015) evaluated the process of creating an exhibition that was aimed at communicating the results of a research project with persons with dementia who were engaged in dementia activism or campaign work. The artworks were created by the persons with dementia, together with a professional artist, and exhibited later. Engaging in the process of artmaking enabled the persons with dementia to express themselves in new ways and the exhibition “caught people’s imagination and attention in a way that a written report or publication could not have done” (Bartlett, 2015, p. 761). Another study (Puurveen et al., 2022) reported the assessment of an exhibition for and with persons with dementia and their care partners. As in the first study, the artworks were created during a workshop. The goal was to create artworks that expressed “what participants wanted others to know about living well with dementia” (Puurveen et al., 2022, p. 623), and to promote power and agency as well as personhood and community engagement (see also Moss & O’Neill, 2019). A slightly different example comes from a project with primary school children who learned about dementia and created and exhibited artwork in which they visualized how one of their own memories could look like when viewed through the perspective of a person with dementia (P. Burns et al., 2021; Pawlicka et al., 2024).

The present study adds to this literature in at least two ways: First, and in contrast to the above-mentioned studies, our focus was exclusively on family members of persons with dementia and their perspective. Second, the exhibits were not created for the purpose of the exhibition but were a result of the creative activities that these family members had pursued outside standardized interventions. This also means that the exhibits had no predefined common goal or message except from the fact that they represented the creative activities that the family members had used to cope with the situation. However, we were confident that the different kinds of perspectives expressed through the different artworks would help to include and present a multiplicity of voices.

The exhibition: a brief overview

The exhibition was entitled “Dementia. A family member’s perspective” (Demenz. Eine Angehörigenperspektive), making clear from the outset that the exhibition focused on family members and their view on living with a person with dementia. Overall, the exhibition pursued three main goals with respect to health communication and science communication: First, to present the results of the study with family members of persons with dementia who had engaged in creative activities to cope with the dementia of a loved one to the public (i.e., *knowledge generation*).

Second, to broaden the societal discourse on dementia by creating awareness that dementia is not only a medical condition and does not only affect the person with the diagnosis but leads to profound changes in personal relations and social interactions – and that creative activities of family members can be a helpful coping strategy for dealing with this difficult situation (i.e., *increasing awareness*). Third, to give the family members but also the visitors an opportunity for expressing their perspectives and for sharing their experiences (i.e., *enabling empowerment*). In short, we wanted to use the arts as a tool to “to explore, understand, represent and even challenge human action and experience” (Savin-Baden & Wimpenny, 2014, p. 1).

The exhibition was presented in the exhibition space of the University Library of Regensburg (Germany) between December 2022 and March 2023 and later moved to the exhibition space of the Spitalarchiv Regensburg (Germany) from April to July 2023. The exhibition space of the University Library of Regensburg is explicitly dedicated to presenting research findings and is open to all research disciplines at the University of Regensburg. The exhibition was specifically designed for this exhibition space, which we describe here (for visual impressions, see the two panels on the right in [Figure 1](#)). The space is a 7 × 18 meters room with glass windows on one side, connecting the exhibition space with the surrounding library environment and allowing people passing by to view the exhibition from the outside. The exhibition was advertised through the local newspaper, on the university’s website, and by sending invitations and the exhibition poster to more than 100 local institutions. The exhibition poster (see the left panel in [Figure 1](#)) was designed to illustrate the Janus-facedness of dementia, that is, both the radical changes and challenges that come with the disease, as well as the possibility to cope with these changes and challenges. In addition, portraying dementia as Janus-faced also implied that there are no “right” or “wrong” perspectives but that the exhibition was aimed at valuing the family members’ point of view.

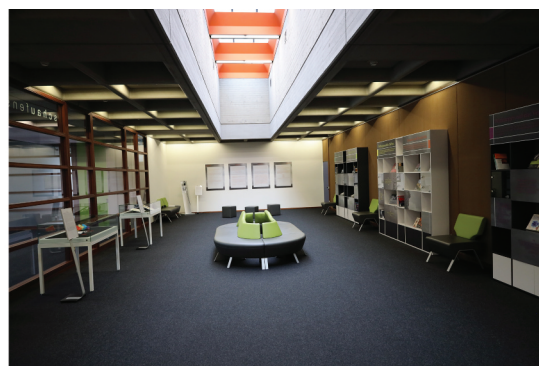
Keeping the goals of knowledge generation and increasing awareness in mind, the exhibition contained the following elements: When entering the exhibition space, participants saw two posters explaining the background of the exhibition and the main results of the interview study on which the exhibition was based (Hutmacher & Schouwink, 2022). The three bookshelves (see the two panels on the right side of [Figure 1](#)) served two purposes: On the one hand, the bookshelves contained quotes from the interviews illustrating the different levels on which engaging in creative activities can help family members of persons with dementia to cope with the disease (i.e., experiential, cognitive, emotional, behavioral, interactional). On the other hand, the bookshelves contained books about dementia and creativity from a wide range of different perspectives (e.g., psychology, medicine, law, sociology, philosophy) as well as books on dementia *and* creativity (i.e., books describing how creativity can serve as a coping mechanism and books that presented creative perspectives on dementia, e.g., a novel, photographs, or cartoons). In addition, the opening event of the exhibition took place in the form of a panel discussion featuring all exhibitors and the curator of



Figure 1. The Exhibition.

the exhibition. Moreover, we offered two guided tours through the exhibition.

With respect to the third goal (i.e., empowerment), all eight participants of the study were invited to contribute to the exhibition; four participants were willing to contribute. These four exhibitors were asked to choose whether they wanted to participate under a pseudonym or under their real names; all contributed under their real names. In addition, the exhibitors were free to choose what kind of exhibits to contribute. One exhibitor contributed a painting, one exhibitor contributed a musical composition and a short story, one exhibitor contributed a happiness diary (that the exhibitor kept together with the person with dementia), a paper garland (with good wishes from friends and neighbors that was used when the person with dementia moved to a nursing home), and a commemorative card (designed after the family member with dementia had passed away), and one exhibitor who had been playing theater contributed the textbook, the costume worn during the theater performance, and a review of the performance published in a newspaper. All exhibits were accompanied by a brief biographical note as well as a description of the creative activity and the respective piece of art. These accompanying texts were written by the exhibitors. Making the opening event a panel discussion was not only based on the idea that this could improve knowledge generation and increase awareness about dementia but also that it could be a platform for the exhibitors to share their experiences and to feel heard and appreciated. The exhibition also aimed at empowering visitors who might be experiencing a similar situation. To make additional voices be heard, the



exhibition included another poster on which visitors could leave notes describing their thoughts and impressions.

In order to investigate to what extent the exhibition achieved the three goals described above, that is, to what extent it served as an effective tool for health communication and science communication, we conducted interviews with both exhibitors and visitors and analyzed the notes that visitors left on the poster.

Method

Participants

All four exhibitors were interviewed (27–72 years, $M = 50.75$, $SD = 19.30$, 1 male, 2 female, 1 diverse). All visitors who had signed up for one of the guided tours through the exhibition were contacted via mail and invited to participate in the study. In total, eight visitors agreed to be interviewed (64–74 years, $M = 67.75$, $SD = 3.15$, 1 male, 7 female). Both the exhibitors and the visitors provided written informed consent. The study was conducted in accordance with the Helsinki Declaration and the University Research Ethics Standards. In Germany, these types of studies do not require ethical approval of an Ethics Committee. All participants were offered a compensation of 10 euros. In addition to the interviews with exhibitors and visitors, we also analyzed the notes ($N = 18$) that visitors left on the poster.

Procedure

The interviews with exhibitors and visitors were semi-structured (Kruse, 2015) and conducted by the first author in

March and April 2023. The interviews with the exhibitors asked why they had decided to contribute to the exhibition, their impressions and insights from the panel discussion, their impressions and insights about the exhibition, and any additional remarks they wanted to share. These interviews lasted between 12 and 34 minutes ($M = 21.92$ minutes). The interviews with the visitors asked why they had decided to visit the exhibition, their impressions and insights about the exhibition, and any additional remarks they wanted to share. These interviews lasted between 7 and 15 minutes ($M = 10.64$ minutes).

Data analysis

We analyzed the data with MAXQDA 2022 (VERBI software) using the method of qualitative content analysis (Mayring, 2014, 2021). In a first step, the first author conducted three separate qualitative data analyses together with a student research assistant who had neither been involved in the previous interview study nor in the exhibition. We decided to conduct three separate data analyses as we assumed that the data sources would potentially provide significantly different perspectives on the exhibition, which should be captured before integrating them. We provide a detailed description of the coding process as well as the resulting category systems including exemplary quotes and code frequencies in the Online Supplement (S1–S5; see <https://osf.io/b2x6d/>).

As an integration of analyses arguably requires substantial knowledge about the project and its goals, as well as the theoretical background underlying the creation of the exhibition, the first author performed this last step together with the last author, who works at the University Library of Regensburg. The last author was not only involved in creating the exhibition but also has several years of experience with organizing and conceptualizing exhibitions from various fields and regarding various topics. The last author first familiarized herself with the data and the three category systems.

Next, the authors independently thought about ways of rearranging and integrating the existing categories into core themes that emerged from the different data sources. Then, both authors discussed different options and agreed upon four core themes and the assignment of the different categories from the category systems to these core themes (for details, see Supplement S6). During the joint discussions, the authors followed two rules: first, to share all thoughts and ideas even if they may sound irrelevant and far-fetched at first glance; and second, not to settle on a conclusion before all concerns and options have been evaluated carefully. After agreeing upon the core themes, both authors jointly worked on the narrative integration of the different aspects within the core themes presented below.

Results

Reasons for the interest in the exhibition

Before describing the core themes with respect to our three health communication and science communication goals, we briefly sketch the exhibitors' reasons for contributing to the

exhibition and the visitors' reasons for attending the exhibition.

Exhibitors

The exhibitors stated five reasons why they decided to contribute to the exhibition. Three exhibitors named the *importance of the topic*, that is, the importance of increasing knowledge about dementia in society, as dementia is a disease that can – directly or indirectly – affect everyone but that is nevertheless still surrounded by a taboo. Three exhibitors stated that they were looking forward to the *exchange with others*: with the other exhibitors but also with visitors of the exhibition who might be going through a similar situation. Two exhibitors mentioned the *general conditions* under which the project was organized as another reason for their participation, such as the fact that the exhibition was hosted at a university or that an exhibition seemed to be an appropriate format for the topic and the intended audience. Two exhibitors stated that they liked the prospect of seeing their creative works exhibited as a means of *self-presentation*, and one other exhibitor stated that she believed she was a *good fit* for the exhibition.

Visitors

All interviewed visitors stated that dementia played a role in their lives in one way or another and that this was a reason for visiting the exhibition: Six visitors indicated that they had had or currently have a *person with dementia in their personal environment* – or that they are getting older and somewhat expect to have a person with dementia in their personal environment in the future (e.g., a spouse). In a similar vein, three visitors considered it possible that they *might be affected by dementia themselves* in the nearer future – and one visitor explained already being affected by early-stage dementia. In addition, dealing with *dementia was part of the professional life* of two visitors. Three visitors also stated that they hoped to *gain a new perspective and new knowledge about dementia* through visiting the exhibition and two visitors said that they had decided to visit the exhibition because they have a *general interest in cultural events*.

Assessment of the exhibition

In the following, we provide an overview of the four core themes that emerged from our data sources with respect to our three health communication and science communication goals: one theme with respect to our first goal of knowledge generation (“The setting is important”), one theme with respect to our second goal of increasing awareness (“Encountering new perspectives on dementia”), and two themes with respect to our third goal of enabling empowerment (“Creating a space for communication and community,” “Being inspired by the exhibition”).

Theme 1: Offering opportunities for knowledge generation – the setting is important

Although exhibitions are an established format for communicating research findings to a broader audience, this does not imply that any kind of exhibition is well-suited

for any kind of topic. Both exhibitors and visitors mentioned two important preconditions that helped to make the exhibition a success, namely that the topic of the exhibition was – given the sheer number of people living with dementia – highly relevant for the public and that it filled an important gap by providing a perspective on dementia that is often overseen. In other words, the exhibition offered opportunities for knowledge generation in that it created a safe and welcoming environment that invited dialogue about a socially stigmatized topic, ultimately enlarging the collective understanding of dementia. For instance, one visitor said that “I would wish that this were much more frequent, that one speaks about it [i.e., dementia] in this way,” and an exhibitor added: “What is missing is a public discourse about the topic. To have initiated this through the exhibition, is a really fantastic aspect.”

In addition, both exhibitors and visitors emphasized the importance of dedicating attention to the detailed conceptualization of the exhibition. This includes various design choices such as the selection of the exhibition space, the arrangement of the exhibits, and the layout of posters and information materials, but also various aspects regarding the content of the exhibition such as the diversity of the creative contributions and the life stories behind these contributions or the decision to make a wide range of literature related to creativity and dementia available within the exhibition. Of course, the exhibition was not perceived in the same way by all individuals. For instance, visitors differed regarding the specific exhibits that they liked the most as well as the specific exhibits that they found less engaging. These differences regarding the individual taste are nicely illustrated by one of the visitors: “The exhibition poster, which was complimented by other participants of the guided tour and which may be very well made from an artistic point of view, was too gray for me.” In a similar vein, one visitor stated that they would have wished that the biographical testimonies of the exhibitors had been longer, while another visitor said that the texts were too much and too long for them. In sum, this suggests it is important to create an exhibition that is able to address different visitors with different tastes as well as different motivations for visiting an exhibition.

While the exhibitors’ and the visitors’ remarks about the exhibition were overwhelmingly positive, one additional aspect emerged from the interviews: Several visitors and one exhibitor mentioned that they would have benefited from additional support, such as the inclusion of a medical perspective or providing information about where to find self-help groups. As the primary focus of our exhibition had been providing an unconventional perspective on dementia by focusing on family members of persons with dementia and their creative activities, we had felt that it was not necessary to provide this kind of standard information, which we assumed to be relatively widespread. However, the comments from the interviews serve as an important reminder that providing background information about the disease and about where to find support would still be considered helpful at least by some exhibitors and visitors.

Theme 2: Increasing awareness – encountering new perspectives on dementia

Visitors appreciated that the exhibition focused on the family members of persons with dementia and provided them access to an unusual and underrepresented perspective. “In particular,” one visitor said, “I liked that not only the disease itself . . . not only the patients were incorporated [in the exhibition] but also the family members,” while another visitor stated that they were “simply interested in the perspective of the family members.” This focus on the family members went hand in hand with the insight that engaging in creative activities can be a strategy for coping with the dementia of a loved one. To give but a few examples, one visitor mentioned that “using creative activities: that appealed to me. I also like to be creative . . . and that helps me tremendously and I always forget all the frustration,” and another visitor added that “this kind of dealing with situations concerns me, as creativity is a part of me.” Moreover, the exhibition did not only serve as a confirmation of the usefulness of creative activities for the visitors, but also for the exhibitors. “I was able to take away a kind of confirmation for myself, that it [i.e., engaging in creative activities] is a good way to go,” one of them said. Such a confirmation seemed necessary as, before the exhibition, “I had never seen . . . others who tried to cope with the situation using creative means.” Overall, these observations indicate that creative activities are a meaningful kind of communication, both for the exhibitors who had created the artworks and for the visitors who experienced the exhibitors’ perspectives.

In addition to these insights concerning family members of persons with dementia engaging in creative activities, the exhibition also opened other new perspectives on dementia, which helped to challenge purely deficit-oriented, decontextualized, and medicalized views of dementia. Three observations are particularly important: First, the presentation of different perspectives and stories by exhibitors highlighted the exhibitors’ individuality, while also acknowledging the existing similarities. “I thought that every dementia is very, very unique and individual and in a certain sense it is,” one of the exhibitors said. “But I found it interesting that there were many similarities between the individual stories.” Second, the exhibition conveyed a positive perspective on dementia in the sense that “life can remain colorful” and that “dementia is not the ‘final destination,’” as two notes on the poster indicated. Ultimately, this also created space for humor, as “there are maybe funny elements that one can laugh about,” as one of the visitors observed. This kind of perspective was also made possible through the exhibitors who “focused on the positive things that are still possible” and who “have responded with patience and understanding to the cases in their own families,” as two visitors described. Third, treating the loved ones with dignity and trying to adapt to the new situation by focusing on resources was closely related to acknowledging the need for self-care and autonomy. This is summed up in the following quote by a visitor: “What I found quite intriguing was that she [one of the exhibitors] was really there for her husband but nevertheless made sure that she could still have a good life.” Another visitor concluded that in case someone in their personal environment would be affected by dementia, “it wouldn’t

do any good to sacrifice myself, but it would be helpful and also legitimate to look for some free space for myself.”

Theme 3: Enabling empowerment: creating a space for communication and community

As stated by exhibitors and visitors, both the panel discussion and the exhibition were characterized by an openness of communication. One of the visitors said that they were “impressed that affected family members speak about it this way and show themselves,” and one of the exhibitors summarized the atmosphere as follows:

I had the feeling that both on the panel and in the interaction with the audience, “spaces” were created. Spaces of communication, but also emotional spaces, because the people in the panel were very open and revealed very intimate things.

The openness of communication created an atmosphere that enabled individuals to share their experiences and perspectives – both the exhibitors and the visitors. This becomes most obvious in the notes that the visitors left on the poster, through which they communicated both coping strategies (e.g., “I enjoy the time with the person with dementia to show her that she does not need to isolate herself”) as well as challenges that they had experienced (e.g., “What do you do when the mother is aggressive and covers her ears not to hear? Difficult situation that turns everything upside down!”).

Participating in the exhibition and particularly also in the panel discussion enabled an exchange with other exhibitors as well as a solidarization among relatives of people with dementia. The exchange with others was valuable and beneficial as “these are such existential experiences that one makes that it is always good to talk about them with a different group of people,” as one of the exhibitors put it. In line with this, one of the exhibitors remarked that “we gave each other the confirmation that we had been in the same situation, even afterward [i.e., now that all relatives have passed away] we still showed solidarity.” Taken together, this suggests that the exhibition created a space for communication and community in which exhibitors and visitors felt that they could express themselves freely and openly.

Theme 4: Enabling empowerment: being inspired by the exhibition

The impact of contributing to the exhibition as well as visiting the exhibition extended beyond the immediate context of the exhibition. To begin with, the exhibition encouraged several individuals to engage in creative activities. One exhibitor explained that seeing the creative activities of the other exhibitors “was an inspiration to also get creative in *this* way,” while one of the visitors said that they had decided “that I want to make a short film on the topic ‘My father and I,’ with particular emphasis on the last ten years of his life in which he had dementia” after visiting the exhibition. Another example of the exhibition inspiring individuals to engage in creative activities were the poetic-philosophical reflections that some visitors left on the poster, such as the following poem:

The question about the self
The self after forgetting
What remains

Am I an accumulation of memories?
Constantly changing, transitory
Never really arrived, never at the beginning, never at the end
“This is not me.”

In addition, the exhibition also led to further intellectual engagement with dementia, such as looking up information on the internet or reading some of the books that were on display in the exhibition. Perhaps the most striking example, however, comes from one of the exhibitors who reported that a question from the audience kept them thinking about the possibility of being affected by dementia themselves for several weeks after the panel discussion: “There was this question from the audience . . . : Are you scared of being affected by dementia yourself? And this is of course a question that sticks with you.” At the time of the interview, the exhibitor had not yet come to a final position on how they would feel when being diagnosed with dementia but emphasized that it seems important to them to think and talk about this question openly. Once again, this demonstrates that the exhibition did not only have an impact with respect to its immediate content, that is, with respect to the usefulness of engaging in creative activities, but also with respect to the more general question of how individuals approach dementia.

Discussion

The art exhibition described in the present paper had three goals: *generating knowledge* about the usefulness of creative activities in the face of a dementia diagnosis of a loved one, *increasing awareness* regarding the multifacetedness of dementia, and *enabling empowerment* by giving exhibitors and visitors an opportunity for expressing their perspectives. Through interviews with exhibitors and visitors as well as through an analysis of the notes that visitors left on the poster in the exhibition, we analyzed how and to what extent the exhibition achieved these goals.

Overall, our analysis identified four core themes. As the first theme indicated, the successful generation of knowledge regarding the perspective of family members of persons with dementia and the usefulness of creative activities did not simply follow from the fact *that* there was an exhibition but was crucially shaped by *the way* the exhibition and the panel discussion were conceptualized. From our perspective, four aspects seem particularly noteworthy and could potentially be used as guiding principles for similar exhibitions in the future. First, the exhibitors were actively involved in the creation of the exhibition: They did not only choose which pieces of art they wanted to display but also wrote the biographical notes and the descriptions of their creative activities that accompanied and contextualized these pieces of art. Second, the exhibition created opportunities for exchange and for sharing additional perspectives, not only during the panel discussion and the guided tours but also through the poster on which participants could leave comments and remarks. Third, the exhibition dealt well with the heterogeneity of the visitors regarding their motivation to attend the exhibition as well as their prior knowledge, which is generally considered an important precondition for the successful implementation of exhibitions in the context of science communication (Schwan

et al., 2014). For instance, the fact that the exhibits represented different art formats satisfied varying preferences of different visitors. In addition, the diverse literature regarding creativity and dementia incorporated within the exhibition allowed visitors to deepen their understanding of aspects of the topic that they found most valuable. Fourth, the exhibition was based on the assumption that there are no “right” or “wrong” perspectives and that it is important to value the family members’ point of view. That is, the exhibition was not meant to establish a master narrative but to allow a multitude of viewpoints. Instead, the exhibition offered – through its conceptualization and design – an environment in which it was possible to encounter and to share very personal and inherently unique perspectives.

As our second theme showed, encountering these perspectives offered new outlooks on dementia that included the usefulness of engaging in creative activities. In a certain sense, visitors of the exhibition encountered the narratives of several *wounded storytellers* (Frank, 2013) who shared their – painful as well as meaningful – experiences of living with a person with dementia. Crucially, seeing the family members’ creative artworks and hearing the associated stories opened new narratives in at least two ways. On the one hand, the artworks challenged dominant discourses around caregiving and living with a person with dementia by shifting the focus from negative or deficit-oriented stereotypes to highlighting moments of meaning and joy. That is, although the exhibitors shared challenging and sometimes even overwhelming experiences, their stories did not end there but also included descriptions of their individual journeys and the ways that they found to deal with the dementia of a loved one. On the other hand, the exhibition demonstrated that there is no contradiction between being a caring family member of the person with dementia and valuing one’s independence and autonomy. While being a family member of a person with dementia certainly changes both one’s daily life and one’s identity, this does not mean that one’s identity can or should be reduced to the role of a caregiver (see also Hautsalo et al., 2023).

As indicated by the last two themes, the exhibition enabled empowerment in the sense that it created a space for communication and community and that it led to inspirations that extended beyond the immediate context of the exhibition. Given that being confronted with the dementia of a loved one is a disruptive life change (Cooper, 2021; Miller-Ott et al., 2022) and given that dementia is still surrounded by a host of stereotypes and stigmas (Low & Purwaningrum, 2020; Rosato et al., 2019), the creation of platforms for exchange and solidarization is still much needed – especially if they have the potential to lead to long-term changes that open new ways of thinking and behaving. This points to an observation that became apparent across core themes: Although the exhibition was primarily aimed at making a case for the usefulness of engaging in creative activities to deal with the dementia of a loved one, the presentation of the artworks and the related life stories also opened various other new perspectives on dementia. In other words, the exhibition fostered the creation of an intimate and invitational space in which it became possible to break the isolation and the stigmas that often surround dementia, which led to both a sense of

community and inspiration. This also speaks to the efforts to view dementia through a disability lens (Shakespeare et al., 2019; Thomas & Milligan, 2018): It showcases that the environment’s reactions to dementia have a significant influence on the way dementia is experienced – and that these reactions can be changed and shaped for the better (e.g., Cooper & Harwood, 2024; Cuadrado et al., 2020).

From a theoretical perspective, two additional points need emphasis. First, our study confirms that an arts-based exhibition can be an effective tool of health communication and science communication, in the sense that it contributes to knowledge generation, increases awareness, and enables empowerment. Judging from the interviews, the impact of our exhibition seem to be in line with the impact of using exhibitions as a tool of science communication observed in previous research, namely fostering the understanding of complex academic concepts (Bartlett, 2015; Curtis et al., 2012; Falk & Dierking, 2000), encouraging alternative ways of thinking and individual reflection (Curtis et al., 2012; Fraaije et al., 2022; Scheffer et al., 2015), and inspiring behavioral changes (Evans, 2014). Looking at the specifics of an *arts-based* exhibition in the context of healthcare, our project underlines the ability of the arts to contribute to the *worlding of possibilities* (Harter & Rawlins, 2011, 2020) in the sense that the arts have the potential to support the expression of self (i.e., of the exhibitors, but also of the visitors who left a note on the poster or who decided to engage in creative activities after attending the exhibition), foster engagement with others (i.e., among exhibitors and visitors), help envisioning otherwise (i.e., encountering a different, more resource-oriented perspective on dementia), and transforming realities (i.e., changing the way one approaches the dementia of a loved one as well as one’s role within this new situation; see Harter et al., 2022). This also underscores the potential of arts-based research especially with respect to topics which are surrounded by stereotypes, and which may therefore be difficult to articulate (Coemans & Hannes, 2017; Fancourt & Finn, 2019; Fraser & Sayah, 2011; Savin-Baden & Wimpenny, 2014).

Second, our study further supports the importance of presenting perspectives on dementia that go beyond the notion that dementia is a neurodegenerative disease of the brain and that help to raise awareness that dementia also leads to profound changes in personal relations and social interactions (Dzwiza-Ohlsen & Kempermann, 2023; Hutmacher, 2023). That is, exhibitions as the one described and assessed in the present paper can be an important step toward moving the discussion about dementia beyond a narrow medical model and beyond an exclusive focus on the person living with the condition. Our emphasis on family members and coping is a potent reminder that stories of disabilities and illness are never solely individual stories of the person living with a condition: They are stories that are co-owned and coauthored by the social environment, such as family and friends. Our focus on family members is not meant to contradict but to complement existing research: We emphasize that fully understanding the situation in which a person with dementia is living requires considering the effects that dementia has on social relationships and family identities. For arts-based research in the context of

dementia, this means that it might be important to consider and include different status groups when designing interventions and activities that make use of creative and artistic approaches.

We note two important limitations. First, the sample of the interviewed visitors was not representative of all visitors. We were only able to contact those visitors who had signed up for one of the guided tours, that is, visitors who had already expressed a particular interest in the exhibition. In addition, not all contacted visitors responded to our invitation for an interview. Hence, it remains unclear how other visitors with a potentially less keen interest in the topic would have responded. Nonetheless, we were able to include some additional voices from the visitors by analyzing the notes that they left on the poster in the exhibition, and the content of these notes fit very well with the interview data. Second, although the interviews with exhibitors and visitors indicate that contributing to the exhibition as well as visiting the exhibition was meaningful, our data do not allow us to measure the effects of the exhibition on attitude or behavior intent. We encourage future studies with larger samples that combine qualitative and quantitative data.

These limitations notwithstanding, the present study provides compelling evidence that an art exhibition on creative activities of family members of persons with dementia can be an effective tool for health communication and science communication in that it can help generate important knowledge, broaden the societal discourse, and encourage empowerment. As indicated by interviews with exhibitors and visitors as well as by analysis of the notes that were left by visitors, the exhibition made a convincing case for the usefulness of creative activities for coping with the dementia of a loved one, stimulated further engagement with the topic of dementia, and created a platform for exchange and solidarity that helped to establish new narratives and perspectives on dementia.

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