

“It is the beautiful things that let us live”: How engaging in creative activities outside of standardized interventions helps family members of persons with Dementia

Dementia
2022, Vol. 21(2) 396–409
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DOI: 10.1177/14713012211041804
journals.sagepub.com/home/dem



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Abstract

Creative activities can have profound positive effects on family members of persons with dementia. Typically, these effects have been studied in the context of standardized arts-based interventions. However, family members of persons with dementia may also engage in creative activities outside of standardized interventions. As these kinds of creative activities have not been investigated so far, the present study tried to fill this gap based on seven semi-structured interviews. The interviews were analysed using qualitative content analysis. The participants reported a wide range of activities that included, but were not limited to, prototypical creative activities such as making music and writing. Crucially, the positive effects extended beyond the experience of engaging in the activities themselves and also included significant changes in cognitions, emotions and behaviour that helped the participants to make meaning of the challenges and difficulties that are associated with the dementia diagnosis of a loved one.

Keywords

arts-based interventions, dementia, creativity, family members, coping

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Introduction

The drastic changes that come with dementia do not only affect the person living with dementia, but also their family and friends (e.g. Bom et al., 2019; Cross et al., 2018). Delivering care to a person with dementia is associated with increased rates of depression (Papastavrou et al., 2007; Pinquart & Sörensen, 2006) and anxiety disorders (for a review, see, Cooper et al., 2007) as well as physical health problems (for an overview, see, e.g. Fonareva & Oken, 2014; Pinquart & Sörensen, 2003; Zhu et al., 2015). However, not only caregiving itself is challenging. Family and friends of persons with dementia also face changes in their relationship to the person with dementia, including the decline of communication and the perceived loss of the person (Albinsson & Strang, 2003; Clemmensen et al., 2019; Hutmacher, 2021; Rudd et al., 1999). Given their increased vulnerability, a variety of psychosocial interventions have been developed that offer support to relatives of persons with dementia. These include counselling and support groups, educational interventions, psychotherapy, formal approaches to care, telecare interventions, volunteer support for carers and multicomponent interventions (for an overview, see, e.g. Gitlin et al., 2015; Jackson & Browne, 2017).

An emerging field of research is the use of the arts to promote well-being of family caregivers of persons with dementia (for a review, see, Irons et al., 2020; see also Cameron et al., 2013). Arts-based interventions offer different creative activities to participants, such as art viewing and art making (Bourne et al., 2019; Burnside et al., 2017; Camic et al., 2014, 2016; Flatt et al., 2015; Hazzan et al., 2016; Lamar & Luke, 2016; Levenberg et al., 2021; Tyack et al., 2017), singing and music (Bourne et al., 2019; Baker et al., 2012; Camic et al., 2013; Clark et al., 2018; Davidson & Almeida, 2014; Hanser et al., 2011; Mittelman & Papayannopoulou, 2021; Tamplin et al., 2018; Osman et al., 2016; Unadkat et al., 2017), dancing (Skinner et al., 2018), taking photographs (Wharton et al., 2019) or poetry and song writing (Baker et al., 2018; Baker & Yeates, 2018; Kidd et al., 2011). Most of these arts-based interventions are designed for the caregiver and the person with dementia to participate together, while far fewer interventions are solely targeted at caregivers (Baker et al., 2018; Baker & Yeates, 2018; Kidd et al., 2011; Wharton et al., 2019).

There is promising evidence that caregivers may benefit from such interventions on different levels. On an *experiential level*, arts-based interventions are often described as positive activities that lead to enjoyment and relaxation (Camic et al., 2013; Clark et al., 2018; Davidson & Almeida, 2014; Hanser et al., 2011; Tyack et al., 2017; Unadkat et al., 2017), ultimately reducing stress (Bourne et al., 2019; Hazzan et al., 2016; Lamar & Luke, 2016). On a *cognitive level*, arts-based interventions have been demonstrated to change beliefs about dementia, the role as a caregiver, and the interactions with the person with dementia (Baker et al., 2018; Baker & Yeates, 2018; Camic et al., 2016; Kidd et al., 2011). In addition, they can also serve as a means for reminiscing, that is, for keeping and bringing back memories (Clark et al., 2018; Davidson & Almeida, 2014; Flatt et al., 2015; Hanser et al., 2011; Kidd et al., 2011). Moreover, arts-based interventions are known to influence the person at their *emotional level*. In particular, engaging in creative activities is sometimes experienced as having cathartic effects (Baker & Yeates, 2018; Kidd et al., 2011), resulting in improved mood and enhanced well-being that extend beyond the activity itself (Clark et al., 2018; Davidson & Almeida, 2014; Hanser et al., 2011; Mittelman & Papayannopoulou, 2021; Osman et al., 2016; Tyack et al., 2017; Unadkat et al., 2017). In addition, arts-based interventions can have an impact on the *behavioural level*, that is, engaging in creative activities can be an inspiration to act and behave differently. For instance, it may lead to the implementation of more creative activities in daily life (Camic et al., 2013, 2016) or to attending more social activities in general (Tyack et al., 2017; Unadkat et al., 2017). Finally, arts-based intervention may enable changes on the *interactional level*, that is, they may change the way one interacts with the person with dementia as well as with other

people from one's personal environment. More specifically, it has been reported that arts-based interventions have a positive impact on the relationship (Camic et al., 2014, 2016; Hazzan et al., 2016; Lamar & Luke, 2016; Tyack et al., 2017; Unadkat et al., 2017) and on communication with the person with dementia (Hazzan et al., 2016; Mittelman & Papayannopoulou, 2021). Furthermore, arts-based interventions support the exchange and the development of friendships with other caregivers (Clark et al., 2018; Wharton et al., 2019).

All studies on arts-based interventions described above were conducted in standardized settings. However, it seems likely that at least some family members of persons with dementia naturally engage in creative activities outside of standardized interventions. This may especially be true when a broad understanding of creativity is applied that defines creativity 'as the novel and personally meaningful interpretation of experiences, actions, and events' (so-called mini-c creativity; Beghetto & Kaufman, 2007, p. 73) and that is consequently not limited to prototypical creative activities such as painting, making music and writing poetry. Against this background, the present study had two main goals. First, to investigate under what circumstances and in what kind of creative activities family members of persons with dementia naturally engage in. Second, to evaluate whether the levels of impact identified in previous studies (i.e. experiential, cognitive, emotional, behavioural and interactional level) also apply to creative activities that are pursued outside of standardized interventions. If this were the case, this would strengthen the idea that creative activities can play an important role in the context of coping with dementia.

Method

Participants

In total, 10 participants were interviewed. As one couple preferred to be interviewed together, nine semi-structured interviews were conducted. As it turned out during the interviews, two participants had not engaged in creative activities themselves, but rather described creative activities that they had offered to persons with dementia. These participants were not included in the analysis, resulting in a final sample of eight participants (24–76 years, $M = 56.60$, $SD = 17.36$, 3 female, 5 male). Participants were recruited through personal contact and by reaching out to self-help groups for relatives of persons with dementia. All participants 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 (see https://www.dfg.de/en/research_funding/faq/faq_humanities_social_science/index.html). All participants were offered a compensation of 25 euros.

Procedure

The interviews were semi-structured. That is, they were based on an interview guide in order to ensure that all relevant aspects were discussed in the same manner across participants. However, the interviewer was allowed to ask ad-hoc questions when it seemed necessary. Each interview consisted of three parts. First, participants were asked to describe their relationship with the person with dementia. In addition, they were asked to describe the onset and the development of the disease as well as the current situation. Second, participants were asked to describe the creative activities that they have used or still use to cope with the situation. Third, participants were asked to explain *whether* and, if so, *how* engaging in these activities has helped them to cope with the situation. In case a specific level of impact was not mentioned in response to this open-ended question, the

interviewer asked additional questions. With respect to the *experiential level*, participants were asked to explain whether and, if so, how the experience of engaging in the creative activity was perceived as helpful in itself. With respect to the *cognitive level*, participants were asked to explain whether and, if so, how engaging in the creative activity had an impact on their thoughts and memories. With respect to the *emotional level*, participants were asked to explain whether and, if so, how engaging in the creative activity had an impact on their emotions. With respect to the *behavioural level*, participants were asked to explain whether and, if so, how engaging in the creative activity had an impact on their behaviour. With respect to the *interactional level*, participants were asked to explain whether and, if so, how engaging in the creative activity had an impact on their interactions with other people. After completing these three parts of the interview, participants were given the opportunity to make additional remarks. The interviews lasted between 25 and 95 min ($M = 50.30$ min, $SD = 27.46$). All interviews were conducted by the same interviewer.

Data analysis

The interviews were recorded and transcribed verbatim. The data was analysed with MAXQDA 2020 (VERBI Software) using the deductive as well as the inductive approach of qualitative content analysis (see, e.g. Mayring, 2014). The analysis was deductive in the sense that a codebook was used that contained the different pre-defined categories. In particular, the codebook included categories to capture the relationship that the participants had with the person with dementia as well as information about the onset and the development of the disease. The codebook also contained categories to capture the specifics of the different creative activities that the participants engaged in. Crucially, the five levels of impact that we expected (i.e. experiential, cognitive, emotional, behavioural and interactional) were also used as deductive categories. However, we additionally used an inductive coding approach to provide a more fine-grained analysis and to identify potential subspects among the broader categories. To ensure the objectivity of the coding process, one interview was coded by two raters. The interrater reliability (Brennan & Prediger, 1981) indicated a substantial strength of agreement (Landis & Koch, 1977), $\kappa = 0.75$. Against this background, one rater coded the remaining material. However, open questions and potentially ambiguous sections were discussed between the two raters. In the following, we first present the individual cases to provide a portrait of the participants and their personal situation. Second, we give an overview over the different levels of impact that engaging in creative activities had across participants.

Results

Individual cases

Mr. L. Mr. L, a 56-year-old musician, spoke about his aunt, who is like a ‘second mother’ to him, as they had been living in the same house since his childhood. His aunt’s dementia became apparent when her husband died 6 years ago. Mr. L was not involved in caregiving. About 3 years ago, Mr. L’s aunt moved to a nursing home, where he visits her until the present day. Mr. L said that it is very hard for him to see his aunt in her present state, as he has the impression that she is gradually fading away. As he explained, his aunt still recognizes him, although she does not speak anymore. That ‘something personal’ has remained makes the interactions with his aunt even more painful for him. As Mr. L is a musician and piano teacher, he did not pick up a new creative activity in response to his aunt’s dementia, but simply continued playing the piano. As he stated, playing the piano has helped him to cope with his aunt’s dementia, especially because music is a strong bond between him and his

aunt. On the one hand, he plays pieces that he formerly played while his aunt was listening and which are thus connected to her. On the other hand, his aunt still responds to music and recognizes melodies she knows from the past. When he is playing the piano, she starts to sing or hum, which gives Mr. L the possibility to interact with her on a non-verbal level when he visits her in the nursing home.

Mrs. B. Mrs. B, a 42-year-old church musician and drama expert, also spoke about her 'second mother', who lived and worked in her family's household since her childhood and who also helped out in the café that Mrs. B's parents owned. The first symptoms of dementia became apparent 11 years ago and became gradually more severe until she died 3 years ago. Until her second mother moved to a nursing home, Mrs. B was highly involved in taking care of her, which she experienced as highly meaningful, but also as extremely exhausting. As Mrs. B explained, her second mother had been working and taking care of other people for all her life. Against this background, Mrs. B saw meaning in her second mother's dementia, as the disease gave her the opportunity to receive all the affection and tenderness that she had given to others. Mrs. B named a wide range of creative activities. She kept a diary, played the organ, began to organize city tours through her hometown and started to collect colourful objects. When her second mother moved to the nursing home, she created a garland with good wishes from the neighbours. In addition, there were several creative activities that she shared with her second mother, such as singing, writing postcards, creating their own idiolect, and keeping a happiness diary. After her second mother had died, she wrote a poem about her life and designed a memorial card.

Mr. E. The now deceased wife of Mr. E, a 76-year-old retired surgeon, was diagnosed with early-onset dementia, age 56. As the symptoms progressed relatively slow, Mr. E was able to keep his wife at home. After a hip injury, his wife was bedridden for the last 3 years of her life. According to Mr. E, he and his wife had an intense and happy life during the first few years after her diagnosis. However, over the course of the years, he became more foreign to his wife until she was 'soul-blind' in the very end, as Mr. E called it. Nevertheless, Mr. E said that being able to stay by her side until her death was important and beautiful to him. During the last years with his wife, Mr. E received great inspiration from fictional literature. In particular, he mentioned *Dr. Bernard Rieux*, the main character in *The Plague* by Albert Camus. As Mr. E explained, there is one scene within the novel in which Rieux remains by the side of a dying child. Mr. E has taken the attitude and behaviour that Rieux shows in this situation as a role model for his own life. In addition, Mr. E made music and listened to music together with his wife as long as she was capable of and interested in doing so. Crucially, he also continued these activities alone.

Mr. J and Mrs. W. Mr. J, who is 56 years old and working in the media industry, and Mrs. W, his partner, who is a 57-year-old trained retail saleswoman, talked about Mr. J's now deceased mother whom both were very close to. Soon after Mr. J's mother was diagnosed with dementia, she moved to a nursing home. However, Mr. J and Mrs. W took her out of the nursing home for the last months of her life in order to give her the opportunity 'to die at home'. While Mr. J and Mrs. W admit that dementia changed the interactions with Mr. J's mother profoundly, both remember the last years of her life as a positive period of time. As they see it, they managed 'to accept the disease', which enabled them to keep a close connection with Mr. J's mother. After the diagnosis, Mr. J and Mrs. W began videotaping everyday situations that they shared with Mr. J's mother. Three years after the death of Mr. J's mother, they used the film material to create a documentary, which was shown in several local cinemas.

Mr. G. Mr. G, a 24-year-old student, talked about two of his grandparents. His grandmother on the mother's side died one year ago, 3 years after being diagnosed with dementia. She lived at home until her death, where her husband took care of her. Mr. G's grandfather on the father's side also had dementia and died 2 years ago, about 4 years after the diagnosis. He spent the last one and a half years of his life in a nursing home and had lost his ability to communicate. Mr. G visited his grandmother quite frequently after the diagnosis. However, he went to see his grandfather in the nursing home only twice, as his grandfather did not recognize him anymore and as he experienced seeing his grandfather in such a state as painful. In order to cope with his grandmother's disease, Mr. G learned a new song on the guitar (Pink Floyd, *Julia Dream*). He only performed the song to himself and imagined that it may describe the state of mind that his grandmother was in. In order to cope with his grandfather's disease, Mr. G walked through the forest, in which his grandfather used to work as a forest ranger, and tried to see the forest through his grandfather's eyes. In addition, he drew a picture, in which he used geometric symbols to visualize different aspects of his grandfather's personality.

Mrs. M. Mrs. M is a 69-year-old pensioner, whose husband was diagnosed with frontotemporal dementia 6 years ago. Since the onset of the disease, Mrs. M's husband has lost his ability to read and write. In addition, his personality has changed: While he used to be a calm and controlled man, he is now very impatient and emotional. When being in public with her husband, Mrs. M feels responsible for him, which puts great pressure on her. During the first years after the diagnosis, Mrs. M experienced the situation as challenging, but managed to keep a close and intimate relationship with her husband. As the symptoms progress, this becomes increasingly difficult. From her youth onward, Mrs. M used to perform in lay theatre groups. After her husband was diagnosed with dementia, she stopped doing so as she believed that she could not afford to spend too much time outside the house. However, she realized later that giving up one of her favourite activities only made her feel worse. Thus, she returned to her old theatre group.

Mr. K. Mr. K is a 74-year-old retired engineer, whose wife was diagnosed with frontotemporal dementia 11 years ago. While the couple managed to maintain a relatively normal life during the first years after the diagnosis, the situation has become increasingly difficult for Mr. K over the last years. As Mr. K stated, he cannot leave his wife alone anymore. Verbal communication has become impossible. Mr. K carries out all the necessary care duties without the support of healthcare professionals. Although Mr. K said that he no longer feels love towards his wife, because she does not respond to him anymore, he considers taking care of her as a responsibility that arises from marriage. Due to the high temporal demand of the care duties, Mr. K has given up several creative activities, such as photography and doing various handicraft work. However, he still keeps a daily diary that includes different rating systems to evaluate his own feelings and his wife's behaviour. In addition, Mr. K has a keen interest in history: He reads books, watches documentaries, does research on the Internet, and is in touch with different archives. In particular, Mr. K is looking for links to his own family's history. From time to time, Mr. K also makes drawings of everyday situations.

Levels of impact

As described above, we expected that the creative activities pursued by the participants could have an impact on five different levels. The five levels of impact are described in detail below. An overview can be found in [Table 1](#), which depicts the number of interviews in which each level of

Table 1. Levels of impact.

Level of impact	Number of interviews	Number of mentions
Experiential	7	33
Cognitive	6	54
Emotional	4	11
Behavioural	4	4
Interactional	6	37

Note. The left column depicts the five different levels of impact. The middle column depicts the number of interviews in which the levels of impact were mentioned. The right column depicts the number of mentions for each level of impact.

impact was mentioned as well as the number of times each level of impact was mentioned throughout the interviews.

Experiential level. The experience of engaging in the creative activities was described as leading to fun and enjoyment, a sense of achievement, intense and liberating feelings, relaxation and distraction. However, participants also emphasized that the creative activities required concentration and effort. For instance, Mrs. M stated: ‘I can relax, although it requires tension and concentration, but a different kind of tension that enables me to set the disease and the relationship aside’. Similarly, Mrs. B said: ‘Even if I was even more exhausted afterwards, there was always a positive result’. In addition, some participants experienced the creative activities as a means to spend time with others. As Mrs. M put it, ‘it is nice to be here and to do something together. To be together with others and to create something with them’. For Mr. G, engaging in creative activities presents the possibility to feel connected to the person with dementia. He described this experience as ‘absolutely emotional. Well, I was in tears, but that was also liberating’.

Cognitive level. As far as the cognitive level is concerned, six different aspects were mentioned. First, creative activities can change *assumptions about dementia*. Mr. L reported that he was surprised to see that some abilities that are deeply rooted within the person with dementia remain intact even in the later stages of the disease. In particular, when referring to his ‘second mother’, he stated that he finds it ‘fantastic that dementia allows this, that music can still somehow be a way to connect’. Through reflection during the creative activity, Mrs. B and Mr. G. have come to see dementia not only as a deficit, but also as a chance to make new and beautiful experiences. While Mr. G argued that dementia can open up the possibility to let go of control, Mrs. B explained that dementia can be an opportunity to receive care and affection by the loved ones.

Second, creative activities can change *assumptions about the person with dementia*. For instance, Mr. G stated that engaging in creative activities helped him to reflect upon the life that his grandfather had before he was diagnosed with dementia: ‘Well, it was clear to me how bad things had become due to his dementia, that he forgot everything and so on, but then I also realized that he had spent the longest part of his life in peace and harmony’. Moreover, Mrs. B said that engaging in creative activities enabled her to see and appreciate the positive and beautiful moments that her ‘second mother’ was still able to have in her life.

Third, creative activities can change *assumptions about the interactions with the person with dementia*. In the case of Mr. J and Mrs. W, rewatching the videos that they had made, led to an important insight: ‘We had always thought that she is speaking with us, that she is talking to us. But when looking at the videos, we realized that the only thing she said was “Yes”’. In the case of Mr. E,

reading literature and relating this literature to his life helped him to redefine his role and his duties in the relationship with his wife.

Fourth, creative activities can change *assumptions about oneself*. Mrs. B used the creative activities to think about her own life, which enabled her to see her life in a more positive light, and to compare her own strengths and weaknesses to those of her 'second mother'. In addition, Mrs. B and Mr. L both claimed that engaging in creative activities increased their sense of control as well as their self-esteem. While Mr. L said that he finds more meaning in his job as a music teacher since he has played music with his aunt, Mrs. B added that the creative activities gave her the feeling that she can surpass herself, which was important as being confronted with the disease gave her a strong sense of powerlessness.

Fifth, creative activities can be a *means to keep and to bring back memories*. Mr. L said, for example: 'Knowing that one of those pieces that I have composed [...], that she was sitting downstairs on the terrace and listened to it: that creates an everlasting connection'. In line with this, Mr. E and Mr. G stated that remembering beautiful, important moments from the past gave them inner strength when facing the disease and that it helped them to see the person with dementia as the person he or she was. For Mr. G and Mrs. B, the activities also served as a means of reminiscence after the person with dementia had passed away. Mr. J and Mrs. W even stated that having Mr. J's mother on video effectively results in her being 'still alive'. In addition, making the videos was a way to document the changes and developments over time. Mr. K uses his diary 'to get things straight, to understand how things were back then, how this or that event happened'. As Mrs. B added, the output of her creative activities are some sort of 'evidence' as they demonstrate that she does not have to feel guilty and that she has done enough to support her 'second mother'.

Sixth, creative activities can *change the general outlook on life*. As Mr. E explained, dealing with literature in the context of dementia enabled him to understand that 'it is the beautiful things that let us live' and that it is important to accept and to embrace one's destiny. Similarly, Mrs. B stated that trying to think about those aspects of life that are working well and that one is grateful for, was a change of perspective that she found helpful for herself. In the case of Mr. L, his aunt's dementia increased the importance of music in his life.

Emotional level. As far as the emotional level is concerned, participants emphasized two aspects. First, creative activities can help to *cope with negative emotions*. Mrs. B said, for instance, that 'writing away' and freely expressing everything that bothered her helped her to deal with the stressfulness of the situation. In a similar vein, Mr. K explained that the partner who has dementia cannot be held responsible for his or her actions anymore, which can be experienced as frustrating. In this context, he considered creative activities to be a potentially important tool for expressing discontent. Mr. G experienced the possibility to consciously relive and re-experience intense emotions as rewarding.

Second, creative activities can help to *change the emotions* that one experiences. Mrs. M stated that she feels 'relieved and happy' after rehearsing with her theatre group and that it helps her to let go of negative emotions after arguing with her husband. Similarly, Mrs. B said that the prospect of engaging in a creative activity was enough to give her confidence. For Mr. G, engaging in creative activities was helpful insofar as it enabled him to get over the state of shock that he was in after visiting his grandfather in the nursing home.

Behavioural level. With regard to the behavioural level, the participants mentioned two aspects. On the one hand, engaging in creative activities can *change the degree to which the topic of dementia is*

present in everyday life. Interestingly, this change can run in both directions. In the case of Mr. G, dementia became less present as a result of engaging in creative activities: ‘Well, it bothered me more before. I thought about it a lot. Through this, I became more relaxed when dealing with it, I guess’. For Mr. J and Mrs. W, having recorded all the videos enabled them to keep the topic alive even after the death of Mr. J’s mother. On the other hand, engaging in creative activities can be a *starting point for changing everyday behaviour.* Mr. L and Mrs. B both reported that the creative activities changed the way they approach their work. In this context, Mrs. B also stated that she took abilities and resources that she saw in her ‘second mother’ as a role model, which enabled her ‘to discover and to develop them in myself’. In addition, she also gave physical exercise a higher priority.

Interactional level. On the interactional level, engaging in creative activities led to changes in the interactions with the person with dementia as well as changes in the interactions with other people. As far as *changes in the interactions with the person with dementia* are concerned, participants named two important aspects. First, several participants experienced pursuing creative activities as an enjoyable way of spending time together with the person with dementia. As Mr. L and Mrs. B emphasized, the creative activity led to a feeling of closeness and connectedness. ‘We considered it as our creative world, it was our world, a world that connected us’, Mrs. B said. In the case of Mr. L, making music opened up a possibility to communicate although verbal communication had become impossible.

Second, engaging in creative activities on one’s own can have a general *effect on the interactions with the person with dementia.* Based on the idea that it was his responsibility to take care of his wife, which he had derived from reading fictional literature such as *The Plague*, Mr. E decided to make as much room as possible for positive experiences in their shared life. In addition, he also stated that having the figure of Dr. Rieux as a role model gave him the strength to do so. For Mrs. M, being able to leave the house in order to rehearse with her theatre group, gives her the opportunity to resolve conflicts with her husband. In this context, several participants stated that they have adjusted their communication behaviour. For instance, Mr. G stated: ‘In the end, I thought that it is not enjoyable to be constantly reminded that one is talking nonsense or that something [that one has said] is unclear. So even if I did not understand what [my grandmother] was talking about, I told her: Yes, yes of course, absolutely’. This approach also helped him to experience the encounters with his grandmother as more positive.

As far as *changes in the interactions with other people* are concerned, participants mentioned three important aspects. First, for several participants, sharing the results of their creative activities resulted in positive feedback from other people. For instance, Mrs. M explained: ‘I get recognition from it, yes. I do. I don’t get this at home [...]’. And Mr. J and Mrs. W said that ‘complete strangers walked out of the cinema [after watching the movie based on the videos that they had recorded] with tears in their eyes [...] and [we got] positive reactions only’. Second, the creative activities gave some participants the opportunity to talk about the disease within their circle of acquaintances. In particular, Mr. J and Mrs. W reported that their circle of acquaintances developed a better understanding for their situation as well as a more positive outlook on dementia. In a similar vein, Mrs. M stated that interacting with the other members of her theatre group gave her a chance to discuss her situation with others. Third, engaging in creative activities can be a starting point for questioning one’s social behaviour in everyday life. For instance, Mr. L stated that he has become more patient with his piano students. Mrs. B started asking herself whether she has ‘an open ear for others’ and whether she could improve in this respect.

Discussion

The present study had two goals: First, to investigate under what circumstances and in what kind of creative activities family members of persons with dementia engage in outside of standardized arts-based interventions. Second, to evaluate whether the levels of impact identified in previous studies also apply to these kinds of creative activities.

As far as the kinds of creative activities are concerned, the participants in the present study named a wide range of different activities that included, but were not limited to, prototypical creative activities such as making music and writing. In contrast to the existing standardized arts-based interventions, the creative activities that participants naturally engaged in were mostly individual and not group activities. Among those activities that were pursued in groups, some involved the person with dementia, while others did not. Thus, our findings indicate that at least some family members of persons with dementia engage in creative coping processes outside group settings and without the support of trained professionals. This is particularly interesting as the group setting is one of the most frequently mentioned factors when it comes to explaining the effectiveness of arts-based interventions (for an overview, see, [Irons et al., 2020](#)).

Often, albeit not always, the creative activities were based on hobbies and interests that the participants already had prior to their family members' dementia diagnosis. While most activities were conducted on a regular basis, several participants engaged in creative activities at specific transition points, such as the person with dementia moving to a nursing home or passing away. This is in line with the idea that art can help to cope with new and unknown situations by reducing fear (e.g. [Camic, 2008](#)). Interestingly, not all participants were involved in caregiving, which supports the idea that dementia poses a general challenge to established relationships that family members and close friends of persons with dementia need to cope with (see [Albinsson & Strang, 2003](#); [Clemmensen et al., 2019](#)) and that creativity might be a valuable means to do so.

Despite the heterogeneity regarding the kind of creative activities that the participants engaged in, there was a considerable overlap regarding the impact of these activities. In line with the results from previous studies (see [Irons et al., 2020](#); see also [Cameron et al., 2013](#)), we found that engaging in creative activities can have an impact on an experiential, cognitive and emotional, as well as on a behavioural and interactional level. All five levels of impact were mentioned in the majority of the interviews. The experiential, cognitive and interactional levels were the three levels that participants spoke about the most. This illustrates that the experience of engaging in a creative activity, which often involves enjoyment, relaxation and distraction, is important, but that the positive effects extend beyond the activity itself and can involve profound transformations in the participants' beliefs and actions (see, e.g. [Baker et al., 2018](#); [Baker & Yeates, 2017](#)). The fact that the participants associated the widely different activities with similar effects may also suggest that the impact of engaging in creative activities does not so much depend on the specific characteristics of the creative activity (e.g. making music versus keeping a diary), but rather on the match between the person and the activity (see, e.g. [de Medeiros & Basting, 2014](#)).

Before setting on these conclusions, however, the findings of the present study should be confirmed by further investigations. This seems particularly important, as there are several limitations to be noted, especially with respect to the heterogeneity of the sample. The participants did not only differ regarding the kind of creative activities that they engaged in, but also regarding their involvement in caregiving as well as the degree of relationship with the person with dementia and the kind of dementia diagnosis that they had to cope with. Potentially, all of these factors could have an impact on the perceived benefits of engaging in creative activities and should consequently be addressed in future studies. Moreover, several participants spoke

about events from several years ago so that their memories may have been prone to errors and distortions.

Nevertheless, the present study provides further evidence for the assumption that creative activities can play an important role for family members and friends of persons with dementia when trying to cope with the situation. The effects of engaging in a creative activity are not limited to the activity itself, but also include profound changes in thinking and behaviour that help to make meaning of the changes and difficulties that are associated with the dementia diagnosis of a loved one. Most importantly, the present study suggests that these positive effects can potentially also be achieved by engaging in creative activities outside standardized arts-based interventions and without the support of trained professionals.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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