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# ART AND COPING IN BRAIN TUMOR Patients and relatives In the Museum Space

# An evaluation study in cooperation between the Department of Neurosurgery of the University Hospital Münster, the Kunstmuseum Pablo Picasso Münster, the Catholic University of Applied Sciences Freiburg and the MSH Medical School Hamburg

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#### Abstract:

Brain tumors are among the rather rare, but often life-threatening tumor diseases. In addition to the stressful cancer diagnosis, those affected are also concerned about having to adjust to possible limitations in cognitive functions such as perception, memory, attention, action planning and communication. Changes in these functional areas can affect patients' sense of identity. In many cases, brain tumours are therefore associated with complex physical, psychological and social stress and are therefore a major challenge for those affected, but also for their relatives.

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In recent years, psycho-oncology has gained in importance as a complementary medical service for the emotional needs of patients and their relatives, in addition to conventional medical measures such as surgery, radiation and chemotherapy. Since 2011, the Brain Tumor Center of the University Hospital Münster has been offering an art-based program for those affected and their relatives in cooperation with the Pablo Picasso Art Museum Münster in the context of psycho-oncological care. The event, which takes place once a month, is accompanied by the psycho-oncologist of neurosurgery, an art therapist and an art educator from the museum.

Out of the results of our scientific study, we present herein the first results of the qualitative analysis. The study was carried out in two fixed groups, each of which completed three consecutive museum visits. The main aspect here is the question of whether the art offer contributes to developing coping strategies by brain tumor patients, relatives and bereaved families and to what extent the art museum is experienced as a protecting place and space for cultural participation. The results show that participants from all groups benefit significantly from the art-based accompanying offer. The situational psychological relief and the strengthening exchange within the group can already be experienced as helpful support during the museum visit. In addition, finished works can function as a communication occasion at home or the memory of the event can be used as a strategy to achieve a positive inner state in times of crisis.

#### Keywords:

Brain cancer, coping, patients, relatives, museum spaces, art therapy

#### INTRODUCTION

Preservation, collecting and research are intrinsic tasks of a museum.

As early as 1975, as part of an innovative museum conference in Frankfurt am Main, questions were asked regarding an entire palette of this type of tasks, and moreover ideas were developed and discussed resulting in a conference volume entitled *The Museum - Place of Learning versus the Temple of the Muses* (original title *Das Museum - Lernort contra Musentempel*, Spickernagel & Walbe, 1976), which was spectacular at the time. This includes contributions that focus on new social tasks for the museum. Over the past four decades, a paradigm shift has taken place in the museum landscape. Low-threshold, visitor-oriented offers were created to address new or previously barely represented target groups. "The 1980s also saw an unprecedented boom in museum start-ups, so that statisticians reported new record numbers of museum visits year after year. The concept of "culture for all" seemed to work<sup>1</sup>. Decades ago, curators conceived exhibitions without even giving a thought to mediation, but today this aspect is taken into account or even brought into focus at the very beginning of curation. According to Düspohl, however, the status quo with regard to the participation and involvement of all social classes, in the sense of "educational justice" in the museum, can still be optimized. In addition, however, Düspohl also refers to a possible dogmatic impetus of museum mediation formats that "exhibit cultural missionary traits" to which some target groups rightly react sensitively<sup>2</sup>. The assertion that museum visits are useful per se must therefore be reflected. There is even the critical question of whether every museum visitor is always a viewer to be culturally instructed. It is possible that a visit to a museum becomes more meaningful through an emerging feeling or encounter, rather than through the initiated museum program or guided activity. Currently, museums and museum concepts are responsible for participatory aspects of accessibility and inclusion.

But what is an inclusive museum? What conditions do museum concepts have to meet in order to be accessible to target groups with special needs? These questions can only be differentiated when target groups are defined, their needs are addressed and taken into account. In the UN Convention on the Rights of Persons with Disabilities, which came into force in Germany on 26 March 2009, the inclusion approach is formulated with the aim "... to promote, protect and ensure the equal enjoyment of human rights and fundamental freedoms by persons with disabilities"<sup>3</sup>. Museums and other cultural institutions are directly addressed in the UN Convention. They are required to take appropriate measures to grant people with disabilities the right to equal participation in cultural life<sup>4</sup>. Based on this assumption, the museum can prove to be a protecting place, a space for encounters and cultural participation.

<sup>&</sup>lt;sup>1</sup> Düspohl, Martin (2007): "The Museum as a Social Factor". In: https://www.bpb.de/apuz/30071/das-museum-als-sozialer-faktor?p=all (accessed on 04.03.2021), p. 1.

² Ibidem.

<sup>&</sup>lt;sup>3</sup> UN Convention on the Rights of Persons with Disabilities. info 2006.

<sup>&</sup>lt;sup>4</sup> *Ibidem*, participation-in-cultural-life-3939, Article 30, para. 2.

It is in this framework that one can situate the project idea "Art and Coping", which aims to establish a psycho-oncological support service for brain tumor patients and their relatives in the museum space. In the context of a cooperation between the Kunstmuseum Pablo Picasso Münster (Head: Prof. Dr. Markus Müller) and the Department of Neurosurgery of the University Hospital Münster (Director: Univ.-Prof. Dr. med. Walter Stummer), the above-mentioned research team developed a program for art education for brain tumor patients under the title "Art as a Means of Life". The offer includes a receptive and an active-creative part. After the one-hour guided tour of the museum, the participants can actively process their impressions in a workshop. In order to describe the effects of this program and to consolidate the program, a scientific study was carried out for evaluation. In addition to the questions of whether the museum is experienced as a protective space, whether the specific conditions in the museum have an influence on communication between patients and relatives, and to what extent the museum is experienced by patients as a place of encounter and cultural participation, this article focuses on the aspect to which museum visits contribute to the development of coping strategies for the affected persons, their relatives and survivors. Standardized questionnaires were also used to investigate these questions; here, however, we will limit ourselves to the qualitative research results.

#### DIAGNOSING A BRAIN TUMOR – A CHALLENGE

With approximately 7,400 new cases per year in Germany, primary brain tumors are among the rather rare but often life-threatening tumor diseases. The prognosis is poor and the relative 5-year survival rates for malignant CNS tumors are 21% percent for men and 24% for women (Robert Koch Institute 2016). Neurooncological therapy consists of resection as far as possible and, if necessary, subsequent radiotherapy and/or chemotherapy. However, due to the location of the tumor in the brain, which for many people is not only the center of thought and action, but also the seat of the personality, this disease often leads to a severe cut in the physical and mental integrity of those affected. Already at diagnosis and in good clinical condition, almost all brain tumor patients are affected by neurocognitive impairments<sup>5</sup>. In a systematic review by Rooney et al.<sup>6</sup>, it was shown that, depending on the screening instrument, patients with brain tumors suffered from depressive

<sup>&</sup>lt;sup>5</sup> Cf. Hendrix et al. 2017.

<sup>&</sup>lt;sup>6</sup> Rooney, Alasdair Grant; McNamara, Shanne; Mackinnon, Mairi; Fraser, Mary; Rampling, Roy; Carson, Alan; Grant, Robin: "Frequency, clinical associations, and longitudinal course of major depressive disorder in adults with cerebral glioma", in J. Clin. Oncol., 29(32), 2011, pp. 4307-12.

symptoms in up to 39% of cases, which in turn were associated with physical functional limitations, cognitive impairments and reduced quality of life. In the course of the disease, about one in five patients develops manifest depression<sup>7</sup>. In addition, studies in outpatient follow-up care show that 44 - 48% of outpatient brain tumor patients showed clear symptoms of anxiety<sup>8</sup> and also in the long-term course it was shown that brain tumor patients were exposed to excessive stress both at the beginning of radiotherapy and chemotherapy, but also after 3 and 6 months. Emotional problems were the most frequently cited for this<sup>9</sup>. These burdens make everyday life more difficult and significantly limit the quality of life of those affected, but also of their relatives. Studies of relatives of brain tumor patients show that they also suffer from distress, anxiety and insomnia<sup>10</sup>.

However, a large meta-analysis by Faller et al.<sup>11</sup> showed that psychooncological interventions, such as psychotherapeutic interventions, can be used in oncological patients.

Individual interventions or relaxation techniques improved health-related quality of life and reduced psychological distress and depression.

In the Department of Neurosurgery at UKM, the psycho-oncological support services for brain tumor patients have consisted of talk therapy, art therapy and a personal training program for many years. In addition, there is the opportunity for the whole family to take part in museum visits at the Pablo Picasso Art Museum Münster. The disease affects the previous rhythm of life. The new everyday life between diagnostics and therapy, hospitalization and being at home lacks any normality and previous life plans are suddenly no longer secure. Since brain tumor disease is often associated with a wide variety of changes in physical, sensory and

<sup>7</sup> Ibidem.

<sup>&</sup>lt;sup>8</sup> Arnold, Staci D.; Forman, Leslie M.; Brigidi, Bart D.; Carter, Karen E., Schweitzer, Holly A.; Quinn, Heather E.; Guill, A.Bebe., Herndon, James E. 2<sup>nd</sup> & Raynor, Renee H.: "Evaluation and characterization of generalized anxiety and depression in patients with primary brain tumors" in: *Neuro Oncol*. 10(2), 2008, pp. 171-81.

<sup>&</sup>lt;sup>9</sup> Rooney, Alasdair Grant; McNamara, Shanne; Mackinnon, Mairi; Fraser, Mary; Rampling, Roy; Carson, Alan; Grant, Robin: "The frequency, longitudinal course, clinical associations, and causes of emotional distress during primary treatment of cerebral glioma", in *Neuro Oncol.*, 15(5), 2013, pp. 635-43.

<sup>&</sup>lt;sup>10</sup> Pawl et al. 2013.

<sup>&</sup>lt;sup>11</sup> Faller et al., 2013 Faller, Hermann; Schuler, Michael; Richard, Matthias; Heckl Ulrike; Weis, Joachim; Küffner, Roland "Effects of psycho- oncologic interventions on emotional distress and quality of life in adult patients with cancer: systematic review and meta-analysis", in: J. Clin. Oncol. 20; 31(6), 2013, pp.782-93.

mental functions, it requires those affected and their families to actively deal with the progressive impairments and to develop new perspectives and horizons.

In relation to these challenges, the perception of art or one's own, active, creative activity can also be a meaningful accompanying offer and provide those affected and their relatives the opportunities for distraction, relaxation, but also orientation and order. It can be assumed that a visit to an art museum can even be specifically effective in this respect, since in this context the sensual perception of art is completely in the foreground. The joint exchange of impressions and feelings about the presented works of art in the group is an opportunity for self-perception and emotional connection. The additional offer to design creatively yourself after the joint visit to the exhibition in the Picasso workshop is additionally supportive. In this way, complaints in the context of functional disorders caused by the tumor disease can be improved and emotional relief can be experienced and shared through the joy of designing. In addition, the creation of artistic results could help those affected to develop new confidence in their own abilities and to create something lasting.

#### FROM THE START TO THE ESTABLISHMENT OF THE MUSEUM PROJECT

At the beginning of 2011, psycho-oncological care by means of conversational therapy began for the first time at the Department of Neurosurgery within the University Hospital Münster (UKM). However, the impetus for the further establishment of art therapy and art-based offers in the museum into everyday hospital life is due to a patient with art historical expertise and a connection to the Pablo Picasso Art Museum. In a psycho-oncological discussion with patients, she addressed the positive effect of a visit to a museum in a phase of life burdened by illness from her subjective experience. In her estimation, her experience could also be positive and a useful offer for other sufferers. The patient's impulse ultimately led to a viable concept between the University Hospital and the Pablo Picasso Art Museum.

In the autumn of 2011, the premiere of "Art as a Means of Life" took place. Since then, about 6-8 guided tours, including workshops, have been held per year at the Pablo Picasso Art Museum for patients with brain tumors and their relatives. The participants are accompanied by the museum's art educator, the treating psychooncologist and the art therapist.

The art-based measure in the museum is offered as part of a psychooncological discussion. The special quality of the group as an opportunity for exchange does not go unmentioned. The relatives of the patients are encouraged to participate in the museum visits as well and to use them as a joint event. It is also explicitly mentioned that both the psycho-oncologist and the art therapist accompany the visit to the museum and that of course no artistic skills are necessary, but that interest, curiosity and experimentation are in the foreground.

Since the pandemic-related closures of the Pablo Picasso Art Museum in 2020 and 2021, the offer has continued digitally. A few days in advance, the registered participants will each receive a material package by post. Participation in the virtual museum tours and creative activities at home is equally high. One advantage is that, for the first time, patients and relatives who have a particularly time-consuming or strenuous journey can also participate.

#### THE MUSEUM LOCATION: THE PABLO PICASSO ART MUSEUM MÜNSTER

The Pablo Picasso Art Museum Münster is Germany's only Picasso museum. With its approximately 600 square meters of exhibition space, it originally consisted of two buildings from the 18th and 20th centuries, whose historic facades were preserved during the museum's renovation in 2000. It houses the world's most extensive collection of Pablo Picasso's lithographs, as well as other Picasso holdings in various artistic techniques and from different creative periods. Large collections of works by his artistic collaborators Georges Braque, Marc Chagall, Joan Miró and Henri Matisse are also among the museum's treasures. In changing exhibitions, the Picasso Museum sheds light on the Spaniard's multifaceted oeuvre by placing his graphic work in dialogue with painting and sculpture. Such cross-references are also explored in the museum's exhibitions dedicated to his artistic companions. In line with the name of its patron, the museum is a house of constant change, which attracts visitors several times a year with special exhibitions dealing with the art of the 20th century (Fig. 1).



Fig. 1 Exhibition room at the Pablo Picasso Art Museum (photo of the museum archive)

The role of art education has changed over the past 20 years and has now become an integral and essential part of the Pablo Picasso Art Museum. In addition to conventional guided tours, art education here also includes dialogical tours, analogue and digital offerings, creative workshops, teacher training and project work at various institutions outside the museum rooms. In addition, a studio - the Picasso Workshop - is available in the museum for creative mediation work.

The Picasso Museum Münster is one of the smaller museums, both spatially and institutionally. The spatially clear situation enables direct contact with the visitors and the creation of a special and relational atmosphere.

For specific groups of visitors, such as brain tumor patients and their relatives, organizational aspects are of particular importance. For example, the size of the group should have a certain clarity, so that each participant not only has a good view of the work, but can also see and hear the art educator well, so that a joint, personal dialogue in front of the artworks is possible.

#### A LOOK AT THE CURRENT STATE OF RESEARCH

Nowadays, the holistic-therapeutic treatment of tumor patients also includes psychosocial aspects, with the aim of coping with the disease and developing coping strategies. In this context, artistic procedures have become noticeably more important, have been included as a recommendation by expert consensus in the S3 guideline "Psycho-oncological diagnosis, counselling and treatment of adult cancer patients" (2014) and are now part of the range of services offered by many hospitals, rehabilitation facilities and outpatient facilities.

Art therapy projects are the subject of numerous current studies, but nontherapeutic, artistic and art pedagogical offers are also increasingly being included, documented and evaluated in treatment. A relatively well-researched area in art therapy is oncology. Controlled randomized trials show that art therapy helps to significantly reduce anxiety and depression, reduces the experience of stress and positively supports a positively changed perception of health and coping with illness<sup>12</sup>. However, some patients in the study by Thyme et al. already had manifest depression before breast cancer, yet 42/143 women actively participated in the RCT. In a review by Bosman et. al.<sup>13</sup> (2021), the English-language literature between 2009 and 2019 is systematically analyzed in relation to the effects of art therapy on anxiety, depression, and guality of life in adults with cancer<sup>14</sup> (cf. Bosmann et al. 2021). The focus was on art therapy as an intervention to reduce symptoms of anxiety and depression and/or to improve health-related quality of life. The prerequisite was that the interventions were carried out with a background of experienced guidance, i.e. by a person with artistic and/or art therapy expertise. This ensured professional guidance on the use and handling of the artistic material and the method required. All artistic disciplines were included, singing, drawing, painting, coloring, sculpting or writing. The focus was to provide an overview of intervention studies that investigated the effects of active art therapy interventions on anxiety, depression and quality of life in adults with cancer. Receptive interventions, or hybrid forms of receptive-active forms of art therapy intervention, were omitted.

Bosman et al. were able to identify four out of seven studies with significant results in terms of anxiety, depression or quality of life. In order not to lose the reference to the study described here, only the studies relevant to art therapy are mentioned here. Three can be described in this context. One of the mentioned studies with a significant effect is the one conducted in 2019 by Jalambadani and

<sup>&</sup>lt;sup>12</sup> Thyme, Karin Egberg; Sundin, Eva C.; Wiberg, Britt; Oster, Inger; Aström, Sture; Lindh, Jack: "Individual brief art therapy can be helpful for women with breast cancer: a randomized controlled clinical study", in *Palliat Support Care*, 7(1), March 2009, pp. 87-95. doi: 10.1017/S147895150900011X.

<sup>&</sup>lt;sup>13</sup> Bosman, J. T.; Bood, Zoë M.; Scherer-Rath, Michael; Dörr, Henny; Christophe, N.; Sprangers, M. A. G.; van Laarhoven, H. W. M. (2021). "The effects of art therapy on anxiety, depression, and quality of life in adults with cancer: a systematic literature review", in *Supportive Care in Cancer* 29, 2021, pp. 2289–2298. https://doi.org/10.1007/s00520-020-05869-0 (Retrieved on 30.03.2021. 23:24h)

<sup>14</sup> Ibidem.

Borji. The team studied women with breast cancer at the Razavi Hospital in the Iranian city of Mashhad. They conducted twelve sessions (once a week, 90 minutes) of Mindfulness-Based Art Therapy<sup>15</sup> (MBAT). A control group was on a waiting list for art therapy. However, she received the standard treatment in the context of cancer. The art-based interventions were led by an artist with psycho-oncological training.

Jang and Kang (2016) likewise investigated the effects of mindfulness-based art therapy (MBAT) in women with breast cancer treated at Wonkwang University Hospital in South Korea. Patients in the MBAT group received 12 weekly sessions of 45 minutes each. The art therapist encouraged the patients to express their inner feelings with the help of the artistic material. Both the intervention group and the control group continued to receive standard oncological follow-up care in parallel. In the course of this study, an improvement in depression scores could be demonstrated. Radl et al.<sup>16</sup> offered cancer patients the intervention sequence "Self-Book" as part of oncological treatment in a hospital in Philadelphia (USA), in the sense of an artistic diary (cf. Rhyne 1996). Both the intervention group and the control group had access to the oncological supportive program. However, only the intervention group created an artistic diary. The participants worked with an art therapist in six sessions of about 50 minutes. The aim of the art therapy offer was to create a self-reflexive and self-designed book. During the first five sessions, the patients were encouraged to relate to a specific theme (safe place<sup>17</sup>, support, strength and virtues, desires for themselves and others). In the last session, the participants were encouraged to design the cover of the book individually.

In a prospective study by Geue et al.<sup>18</sup>, a group intervention for adult cancer patients after completion of acute treatment was carried out artistically and experimentally over a period of 22 weeks (once a week, 90 minutes each) under the guidance of an artist with additional psycho-oncological qualifications. The design

<sup>&</sup>lt;sup>15</sup> Monti et al. (2006) developed an eight-week psychosocial group program for women with cancer called "Mindfulness-based art therapy" (MBAT). Conceptually, MBAT uses the principles of Leventhal's theory of self-regulation. The program integrates meditations and includes verbal and artistic non-verbal expression. In the 2.5h sessions, body scan meditations and various artistic topics are stimulated or instructed. The focus is on reducing stress.

<sup>&</sup>lt;sup>16</sup> Radl, Donna; Vita, Maureen; Gerber, Nancy; Gracely, Edward J; Bradt, Joke: "The effects of Self- Book((c)) art therapy on cancer-related distress in female can- cer patients during active treatment: a randomized controlled trial", in *Psychooncology*, 27(9), 2018, pp. 2087–2095.

<sup>&</sup>lt;sup>17</sup> The 'safe place' stabilizing intervention technique (cf. Reddemann, Luise: *Imagination as a healing force*, Stuttgart, 2007, Klett-Cotta).

<sup>&</sup>lt;sup>18</sup> Geue, Kristina; Buttstaedt, Marianne; Richter, R.; Böhler, U.; Singer, S. (2011). "One Art pedagogical group intervention in outpatient psycho-oncological care. Psychother", in *Psych. Med*, 61, 2011, pp. 177–181.

of an individual artistic book, free and structured work with pictorial materials were the contents of the intervention series. The Hospital Anxiety and Depression Scale (HADS), a questionnaire on coping strategies for illness (FKV), and the Scale for the Assessment of the Subjective Burden of Chronic Illness (PACIS) were used as research instruments. Although there were no glaring changes in anxiety and depression, participants reported that participation in the intervention was a positive experience in itself. However, this was not further specified.

Among the studies in the aforementioned review that looked at anxiety, half found significant improvements in anxiety scores, while the other half did not. In terms of depression, two studies found a significant improvement in depression scores, one study found no improvements. Four out of six quality of life studies showed a significant improvement in quality of life after the art therapy intervention. Three studies found no significant results in terms of anxiety, depression or quality of life. Nevertheless, all participants considered the experience to be valuable for their well-being.

Summarizing Bosman's review, art-based interventions under the guidance of professional art therapists and/or psycho-oncologist-trained artists and/or art educators may have positive effects on anxiety, depression, and quality of life in adults with cancer. With regard to the interventions in the context of the review presented by Bosmann et al., the comparability of the intervention concepts and the media setting of the successful studies is remarkable. The Artistic *Diary* as an Artistic Method and Mindfulness-Based Artistic Interventions have a positive effect with regard to art therapy support for oncological patients.

In addition to the research into active art-based or art therapeutic interventions for cancer patients, it is also relevant to take a look at further museum research with regard to the study presented here. The visitor and his or her experience are always at the center of research. In 1993, for example, Kaplan, Bradwell and Slakter put forward the thesis that museums can certainly be recreational spaces. As part of two different studies, they examined 124 visitors and a comparison group of non-visitors in 11 art museums. "They wanted to prove that you don't just educate yourself in a museum, you also relax. However, the factors "distraction from a routine", "being in another world", "fascination" and "feeling in

harmony" do not confirm absolute values, but these could differ. The higher they are, the stronger the moment of recovery"<sup>19</sup>.

During the research on the relevant topics regarding the study project, a specific intervention offer in the museum in the context of oncology was particularly relevant. Deane et. al. published in 2000 in the Canadian Oncology Nursing Journal a study with 21 adult, mostly female, predominantly breast cancer patients. The age range of the participants was from 30 to 70 years. Participants took part in a 16-week program at an art museum (two-hour program, once a week). Museum art was used receptively for reflection or resonance in order to provide access to the current emotional experience and to enter into a joint exchange/conversation about it. The participants were examined according to the program with open-ended questions (qualitative content analysis) as well as with a Likert scale<sup>20</sup> via telephone interview/questionnaire. During the intervention, the participants were able to distance themselves from the condition and talk about their feelings. The process support and the exchange among each other were of particular importance<sup>21</sup>.

#### **S**TUDY DESIGN

The research project is designed as a formative evaluation. Since people with brain tumors often find themselves in an existential crisis situation, they need a safe and secure place where they can develop new perspectives and make social contacts. The project team assumes that the museum can thus be a protective place and also a place of cultural and social participation.

The study investigated the questions of how the specific conditions in the museum impact the affected persons and the contact between those affected and their relatives, and whether and to what extent art education is suitable for supporting brain tumor patients in the development of coping strategies. In the sense of a formative evaluation, the results of the data collection were simultaneously used for the further development of the "Art as a Means of Life" program.

<sup>&</sup>lt;sup>19</sup> Schuster, Martin; Ameln-Haffke, Hildegared: "Der Museumsbesuch al emotionales Erlebnis -

Erlebnisverläufe im Kunstmuseum Bonn", in Schuster, Martin; Ameln-Haffke, Hildegard (editors): *Museums - Psychologie. Erleben im Kunstmuseum*, Göttingen, 2006, Hogrefe, p. 228.

<sup>&</sup>lt;sup>20</sup> In the narrower sense, the Likert scale is used to measure the attitude of a respondent towards a topic.

<sup>&</sup>lt;sup>21</sup> Deane, Karen; Fitch, M.; Carman, Marianne: "An innovative art therapy program for cancer patients", in *Canadian oncology nursing journal*. 10, 2000, pp. 147-157.

The study was carried out in two fixed groups, each of which completed three consecutive museum visits. In order to identify, differentiate and describe the specific effects of the program, we used research instruments from qualitative and quantitative social research.

Here we report on the results at the qualitative level, using three complementary methods. In the six events, each of which consisted of a museum tour and an aesthetic-artistic-practical part, we used the research method of *passively participatory observation*. The observation was carried out by a total of two researchers over the entire course of the event. The passively participatory observation made it possible to perceive and grasp the special atmospheric conditions in the museum and the communication and interaction processes between the participants and the art educator associated with art education, as well as between the participants themselves; as well as the interaction processes between the participants and the participating psycho-oncologist and art therapist, who helped the participants from the clinical therapy. Furthermore, the interactions between the team members: art educator, psycho-oncologist and art therapist could also be perceived and recorded.

Participating observers are inevitably part of the field of investigation and thus inevitably influence the object of investigation. In order to keep this effect as low as possible, the observers did not actively interact with the people in the field on their own initiative and did not otherwise participate in the event. They participated passively.

The observation was carried out in an open form, there were no predefined observation criteria. In order to record the perceptions of the observation, keywordlike field notes were created during the event and a memory protocol in the form of a dense description was created immediately after the event.

Just after the conclusion of each event, we used the research instrument *group discussion/ group talk*. These took place exclusively with the participants, without the presence of the art educator, the psycho-oncologist and the art therapist. It was hoped that this would lead to an open and critical exchange between the participants in the group discussion. The group discussion conducted directly after the event enabled us to capture the direct experience of the participants during the event, which had not yet been overlaid by other impressions. The chosen form of the survey enabled the participants to remain in the familiar and reassuring group, in contrast to an individual survey. We hoped that this would lead to a greater openness in the articulation of their experiences in the event as well as a mutual encouragement to describe their own feelings and thoughts.

Also just after each event, a *guided interview* was conducted with the art educator, the psycho-oncologist and the art therapist who initiated the series of events. In the interviews, the direct experiences, perceptions and impressions from the event could be recorded, as these could not yet be comprehensively reflected and classified at that time. The guideline-based interview enables the interviewee to enter into his or her own reflection process oriented towards the event and the topic. At the same time, it is provided with a structure to which they can orient themselves. In this way, the process of reflection and the thoughts accompanying it can be grasped and not only the quintessence of a completed process of reflection<sup>22</sup>.

The psycho-oncologist participating in the event and the art therapist are involved in the clinical therapy of the participants and also motivate the patients and their partners to participate in the events in the museum activities also outside the framework of the study.

One day after the last event, we conducted a *guideline-based narrative interview* with all participants. For this purpose, we visited the participants at a location of their choice, usually this was their home. The guideline-based, narrative interview is characterized by a high degree of listener orientation and at the same time has a low degree of external structuring. The opening question used, as well as all subsequent questions in the guide, have the character of a narrative challenge. The main part of the interview consists mainly of spontaneous narratives of the interviewee. The interviewee is given space until he or she ends telling the story on his own. In the guideline-based, narrative interview, the interviewees are addressed as experts and theorists of themselves, which means that there should also be room for self-interpretations in the interview (Schütze, 1987).

Through the guideline-based, narrative interviews, we hoped to gain information about the experiences in the receptive and active engagement with artistic works during the event, as well as to be able to record possible effects on the individual experience of illness and possible influences on communication with relatives. These interviews ranged in duration from 20 to 81 minutes. Each interview was recorded with an audio recording device and then transcribed.

#### **S**TATISTICS

The evaluation of the qualitative data was carried out with the aim of qualitative content analysis, based on Mayring (2008) in computer-aided form. For this purpose, the program MAXQDA 12 (MAX Qualitative Data Analysis) was used.

<sup>&</sup>lt;sup>22</sup> cf. Helfferich, Cornelia: Die Qualität qualitativer Daten, Wiesbaden, 2005, Springer..

In the evaluation process, the data material was coded and key categories were successively developed. With the exception of the categories "Coping" and the supracategory "Methods of Art Education", this was done inductively. The data was evaluated in a circular manner. After each event in the museum, the collected data was processed, coded and evaluated in a first step. The findings were presented to the implementing team, i.e. the art educator, the psycho-oncologist and the art therapist, before the next event and reflected on together. This allowed the lessons learned from the previous event to be incorporated into the next event. This approach made it possible to gradually develop the series of events "Art as a Means of Life" on a methodologically didactic level and to integrate elements that seemed suitable for approaching open questions that emerged in the course of the research process. The questions that arose in the research process could be partially integrated into the further research process.

One of these questions was what effect can one get when, on the basis of a suitable work of art, participants are specifically encouraged to create individual references to the experience and to coping with crises and traumatic experiences.

The examination was carried out with two groups on 3 consecutive appointments each. At the end of the six events, the final overall evaluation took place.

#### **CHALLENGES AND LIMITATIONS**

The evaluation study was not conceived as a self-contained project, but explored the existing, already ongoing offer "Art as a Means of Life", in which participants take part in a guided tour of the exhibition rooms of the Picasso Museum and then enter into their own artistic practice in the museum's Workshop. Usually, participation in the offer is open, so that there may be a different group composition at each date. To us this seemed to be unsuitable for the study goal. As a study-related intervention in the existing project, it was therefore agreed with the participants that two groups would be formed, each of which committed itself to participating in three consecutive dates. The participants who could not decide to do so were asked not to take advantage of the offer during the research phase. It was also envisaged that new participants would be recruited for the study.

Field studies entail that challenges arise in the implementation that have not been considered beforehand and that need to be integrated. This is due to the fact that real life follows different laws than the constructions devised by the researchers. Thus, challenges arose in the research process, consistently from the reality of life of the participants and the person-centered approach of the project managers. The resulting changes inevitably and ineluctably had an impact on research.

In the time between the conception of the research project and the actual implementation, participants of the group died due to their illness. The relatives felt a great need to be able to continue to participate in the museum events, as the offer gave them support in the situation of loss they had experienced. The team decided that the relatives affected by the loss could not also be deprived of the support of the group. It was therefore decided that they could continue to participate in the event "Art as a Means of Life". As a result, the study design changed in such a way that in addition to the group of brain tumor patients and the group of relatives, there was also a group of survivors. We assumed that each group associated its own specific needs with the supply and that specific effects were also to be expected. Furthermore, this change in the participating groups influences the offer, so that we had to extend the study to a third group (survivors).

Another challenge was that it was not possible for all participants to participate in all three consecutive events, mainly for health reasons, but also because relatives had to attend work appointments. As a result, the group constellation for each of the three events was not the same, and there was a lack of participants in each case. The vacated places were not filled with new participants. Another special feature was that in the second group, several participants were unable to attend the first appointment and did not answer the questionnaire on quality of life that was completed before the first event. Furthermore, contrary to what had been planned, not all of the group of those affected took part in the event together with their partner. This had to be taken into account in the evaluation.

After the first date of the event, a couple from the second group decided not to attend the other two appointments because they "did not like the offer, contrary to expectations". Since we were interested in their motivations from a research point of view, we were able to persuade them to conduct the guided interview with us, which was conducted after the third date of the event, as with all other participants. As a result, the time gap to the experience was considerably longer for these two participants.

The group that took advantage of the museum's offer "Art as a Means of Life" and was thus the subject of the study shows a high degree of heterogeneity. Their experiences with the offer varied: some used it for the first time at the beginning of their studies, while others had been participating regularly for several years. Some participants had only been confronted with the disease for a relatively short time, while others had been diagnosed some time ago. Some participants were confronted with a recurrence, some were in acute clinical treatment and still others felt they were on the road to recovery. Individual health status inevitably has an impact on both the needs associated with the offer and the individual benefits that participants derive from the offer. Due to the small number of cases, we decided in the present study - despite these influencing factors - to consider them as a whole and only differentiated according to the basic status: participants with brain tumors, relatives of people with brain tumors and survivors of brain tumor patients who had already participated in the event during the lifetime of the relative. We have considered these three subgroups of participants separately.

#### A TYPICAL AFTERNOON OF STUDY AT THE MUSEUM

The exhibition "Marc Chagall – The Awake Dreamer" with around 120 colourful paintings, drawings and graphics ran from 13 October 2018 to 20 January 2019 and coincided with the study period. Chagall was acquainted with Picasso and they maintain a regular artistic exchange, even though their work was very different. At the same time as the Chagall exhibition, works by Picasso were shown in the museum in a surrealist context and were thus able to enter into a dialogue with Chagall's works. Marc Chagall (1887-1985) has gone down in art history as a painting dreamer. In his colorful works, the laws of gravity and logic seem to be suspended. Like hardly any other artist, he succeeds in transforming reality into a romantic dream world in which he lets people and fantastic creatures float together through his pictorial spaces. Chagall's windows are widely known for various religious spaces in Mainz, Reims, Jerusalem, Nice and Zurich.

In the exhibition, the group looked at about 3-4 selected, large-format and highly visible works. The participants first organized themselves standing or sitting relaxed in front of the picture. It was important that the recipients were able to perceive by seeing and hearing. The art educator first gave the participants time to look and then built a bridge with a quote from the artist and small anecdotes from his life. In this way, the artist, but also the person Marc Chagall, became tangible for the viewer. After one of these introductions, the art educator asked small questions about individual works, which invited dialogue and independent discovery. In Chagall's particular case, a pictorial comparison of related works was a good idea in order to find Chagall's typical pictorial elements and bring them into a narrative pictorial context. The participants were encouraged to speculate on interpretations of individual elements, which were then passed on in the conversation.

The group was very inspired by Chagall's works and entered into an intensive exchange about the paintings. The viewers were particularly attentive when they

heard about Chagall's persecution by the National Socialists and the death of his beloved wife, and this information was linked by the art educator to specific works by Chagall. The presence of these images gave the group visual access to the pictorial processing process and the visible support that Chagall found in painting in times of heavy stress. After the time together in the exhibition (approx. 45 min), the group was given about 10 minutes to make their own discoveries, alone or in small groups. After the dialogue in front of the paintings, the art educator invited the group to search for favorite motifs in Chagall's works and to sketch them in pencil on paper (e.g. floating couples, animals and sleighs, flowers, biblical scenes, circus scenes ...).

After visiting the exhibition, the museum moved to the workshop of the Picasso Museum. After the participants had provided themselves with drinks and looked for a seat to relax, the art educator explained the other possibilities for those who want to try out their creativity. Since Chagall also used the typical pictorial motifs in his window paintings, which the group had become acquainted with and sketched in the exhibition, glass stains were now to be used to create their own window painting, which was based on Chagall's works. The sketches were placed under a thin sheet of plastic, traced in the contours with texture paste and painted with glass paint. In the end, all the works were glued to a window and looked at appreciatively by the participants before they were packed up for transport home. The majority of the participants were happy to take the opportunity to take a souvenir photo of the ensemble of designed works.

#### RESULTS

The open group discussion after the event enabled the participants to further structure themselves the conversation and to choose the content focus that is important in the context of their experiences. The group discussions lasted a good 30 minutes. The length of the six group discussions varied between 24 and 41 minutes. The group conversation was recorded with an audio recorder and then transcribed.

The research team's guided interviews ranged in length from 20 to 54 minutes. Each interview was recorded with an audio recording device and then transcribed.

On the qualitative level, we investigated the extent to which the visits to the events in the museum support the participants in developing coping strategies in dealing with the tumor disease, as well as which methods of art education are conducive to this process. In this article, we will limit ourselves to presenting the aspect of "supporting coping strategies". Further findings will be published elsewhere. The results are divided into participants with brain tumors, relatives and survivors.

In addition to the aspect of support in the development of coping strategies, the evaluation showed that the participants immediately perceived the offer as relieving and helpful, without these aspects being attributable to the development of coping strategies. Since the participants considered these effects to be of great importance, we decided to include these aspects in the study. Thus, the entire study comprises three overarching categories:

- 1. Training of coping strategies
- 2. Helpful and useful effects for the participants and
- 3. Methods of Art Education.

In the evaluation, we differentiated between the participants' selfstatements in the guideline-based, narrative interviews and in the group discussions, as well as the observations and statements of the project implementers in the guideline-based interviews at the end of each event. In the evaluation of the coping strategies and of the helpful and useful effects, we rely on the participants' self-statements. Wherever we accept the perspective of the project implementers or the observational perceptions of the researchers, this is indicated accordingly.

Furthermore, the presentation of the results focuses exclusively on the category "Training of coping strategies".

# DEVELOPMENT OF COPING STRATEGIES IN BRAIN TUMOR PATIENTS CHANGE OF PERSPECTIVE - EXPERIENCE OF NORMALITY

In those affected by a brain tumor, the desire or need for "normality" is quite pronounced. "Normality" here refers to individual ideas of a participatory, family and social life that is not shaped by the disease. This also includes the need to be able to give space to other things in addition to the disease. This applies both to social interaction and to one's own world of thoughts. It is perceived as normality not to think about the disease, because illness and also health are only parts of life, besides which other aspects (should) have space. Moments in which it is possible not to think of and about the disease, or moments in which it is not the content of the social encounter, are perceived as relieving. Participation in the events at the museum helps to broaden one's own perspective in this regard.

During the event, participants with brain tumors can experience that they succeed in living a bit of "normality" again. This encourages them to find their own strategies with which they can cope as well as possible in life situations shaped by the disease. The perception of the other participants helps to release the numbness after the diagnosis and the subsequent therapeutic interventions.

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The event itself can also become part of the newly gained normality, in which in the museum the illness fades into the background and a "normality" freed from it is experienced.

"And I was also very impressed by how courageously some (..) actually everyone is dealing with their illness and (..) a bit of normality was brought in there that I thought: "Yes, well, you also have certain symptoms and you have to see how you can best cope with them, but it is possible." (G1-F3\_PA-B 53-53)

"... a few brushstrokes or, no, to go down through the museum and then get the explanations that [the disease] is forgotten. That's really in the background and that's what happens again and again and that's why I think it's a bit normal. Normality actually comes out: I don't deal with my illness because [] this is not my life, but this is a part [] and before that I didn't just deal with the fact that I was healthy, but that was also just normality []. And that's exactly how it is now and I actually find that really heart-warming and soothing." (G1-F3\_PA-S 16-16)

"R: And the great thing was also to see the people and ask themselves "Who is the patient of this"(?) " Are these patients at all" (?) and if there was a couple "who is the (.) Who is the patient"? They all looked so normal and that's when I thought, well, I didn't feel normal at ALL. I didn't feel beautiful anymore either. So it wasn't nice in the (.) because nothing was normal anymore and these were normal people and that was also the feeling that you would get there again. (I:Mh.)" (G1-F3\_PA-R 12-12)

The event in the museum can contribute to the fact that the illness and thus also the changed life situation can be accepted as a new reality of life, which can have a positive influence on the quality of life. In addition to the losses associated with the disease, the acceptance enables patients to perceive and feel the positive sides of life and being that continue to exist, so that life can be evaluated as positive despite the limiting changes. The event's appreciation of art and the free space for conversation contribute to this.

"Life is still beautiful because you see it very differently than it used to. /mhm/ And you just have to get involved with it and that's just (.) a lot, I guess a lot. This view is also due to the meeting in the museum, the visits and the conversations." (G1-F3\_PA-HS 60-60)

#### **NEW EXPANDING PERSPECTIVES**

The participants' engagement with the personality of the artists, their life strategies, lifestyles, attitudes towards life, as well as with the curated themes or individual works, have the potential for a comprehensive space for reflection that enables the participants to transfer into their own, current life situation. To experience in the event that neither the lives of the artists nor their work can be equated with perfection and are usually not free of doubts and crises encourages a change of perspective on one's own life. This leads to the development of new valuation perspectives and provides impetus to tackle new things. Under certain circumstances, this can open up a broader perspective on the given life situation, on the partnership or family and the creative possibilities. In the examination of the works of art and the artists, one's own, current potentials are discovered, they can be seen as individual, own possibilities. Although the life situation of the artists and their aesthetic grasp is seen as more comprehensive and different from one's own, the transfer makes it possible to accept one's own life situation with the illness. This can change the attitude of wanting to hide it and encourages people to go out in public and be visible. To what extent certain works and artistic personalities offer a special potential for this still needs to be investigated.

Likewise, the attitude of accepting one's own and individuality, which is discovered in the artists, can be taken into everyday life.

TNw5: "At some point, I don't know how long ago, there was an exhibition by one of Picasso's admirers, who always doubted himself and uh, Picasso was someone [] who even found a little bit of scribbles on a napkin beautiful. And that's when I said to I don't know if to (Britta Lauro [art educator]) or anyone else: "We should all be a little more Picasso."

And since then, both when I'm artistically active at home or for life, I'll say a nice motto:

04:20 [murmur of agreement]

"We should all be more Picasso," believing in what we do. Just like it. No matter what it is. [emphatically] (Gr-TN G1-F1 61-64)

"TNm: You have to say that the disease, so it's basically not a disease for one person. It's a disease that really, when you're in a relationship, that partnership really hits very, very deep at the core and () that helps both of you. If you do something together somewhere, then just get to know what a Picasso did and by what means and what you yourself can deduce out of it. This means again and again that you look for points and then also say, what else could you do,

possibly out of this whole () I mean peace [peace was the curated theme of the exhibition], so peace basically means among each other in the partnership, but for this to happen, each individual must also carry his peace within himself, and these are topics, I think they are very well promoted. That you can also find ... in yourself.

And just say, well, that's the way it is now. We have to accept it, but that does NOT mean that we should let our ears down, but we should basically put our ears up and say, ok. We will continue (...)" (G1-F1 GrD 141-142)

"TNw5: Also what you just said about the "perfect" is very important. I didn't do a lot of art before, even though I have a little talent, because I always had this perfectionist urge. And here I was able to get involved in saying: okay, it's not perfect, it has its own (pause 5) dynamic [word-finding supported by the group]. Even with drawing. I didn't try to draw people photorealistically anymore.

Instead, I noticed that the pictures I painted in the hospital, half a block full, were all different. Just not perfect, and they had a lot of expression. Because, for example, the eyes were good, or because there was a gap between the figures, even though they were really only scribbled, because this was fit. And all of our lives, whether children, parents, partners or those affected ourselves. Life isn't perfect after that. To realize that I can move away from perfectionism in art means: we accept our life, which has moved even further away from "perfect". (F1-G GrD 146-154)

The constellation of the group, which also includes bereaved relatives, also means that participants with brain tumors are confronted with death. The bereaved will inevitably convey to you that the treatment cannot be successful either, which is sometimes experienced as stressful. On the other hand, this circumstance also makes it possible to come to terms with one's own death. The idea of one's death can be accompanied by a concern for that person's partner, and the question of whether and how he/she can deal with it. Through contact with the bereaved, it can be experienced that life goes on for them and that they also develop joy of life again. Being able to experience this can broaden one's perspective on one's own death and be perceived as relieving. It can therefore help to accept the disease, as well as the option of not surviving it, because a "post-mortal" life perspective for the partner can be seen.

"... it's great when he's ready today to be able to say, yes, go on holiday alone and then yes. And it goes on. So to know that according to the motto man, um, that's what my wife is also facing It's not just what comes to me, but it affects my wife too, (...)" (G1-F3\_PA-HS 28-28) In contrast to the feeling that thinking about the illness at home is perceived as stressful, as it is often not possible to get out of one's own circle of thoughts, it is easier to think about the illness in the context of the museum event. Inside the museum, there are always impulses that stimulate or distract a change of perspective and enable the participants to get out of their own thought patterns. This experience makes it easier for the participants to think about the disease and to exchange ideas about it. In this context, a special significance is attributed to the preoccupation with art.

The museum visits are seen by the participants with brain tumors as a help to master their own life situation and to cope with disease crises more easily. In addition to the art, the other participants contribute to this to a considerable extent. The intense encounters remain in the memory and such memories can be called up in crisis situations and give confidence. The group of participants is experienced as a social space to which great importance is ascribed.

#### SOCIAL PARTICIPATION

Encouraging social participation was described as an essential aspect. This is important because participation is severely restricted by the disease, because often the affected couples no longer dare to do so. The personal invitation and encouragement from the psycho-oncologist is experienced as a bridge to take a first step towards participating in a public event in a protected setting. Participation in the event at the Picasso Museum requires participants to leave their home shelter and retreat and walk through the bustling city center to the museum, as there are no parking spaces directly at the museum. In addition, the event takes place during the general opening hours, so that you can also come into contact with other visitors. They immerse themselves in normality and experience that they can survive in public. You will not be stared at, nor will people turn away from you. In addition, they experience that a 90-minute event in public space does not overwhelm them. The experiences they make in connection with the museum visits give the participants with brain tumors the confidence and confidence to be able to take advantage of other public offers or events again. It is also described that this also has a positive influence on the partnership.

"I: Could you describe again what influence these events have on your mental well-being in general, or whether they have any influence at all?

B: Yes, definitely, well, as I just said, it was already like that after the first time. The feeling that I can trust myself to do this has given me such encouragement. That now it's time for me to turn to other things again." (G1-F3 PA-B 203-206)

"... But because it's in the middle of the city, first of all you're looking for a parking space, you see a lot of young people and the same when you go there. You meet so many young people. That's very beneficial /mhm/ And um yes you also have the feeling from this room actually um, that what is really personal doesn't come out of there /mhm/. But on the other hand, there are also normal visitors. That basically means that these are people who have really decided on art in order to look at it, who have done it quite consciously and um, but who you don't perceive as strangers at all, /mhm/ but you rather have the feeling that they are busy with art just like you yourself /mhm mhm/ um that's actually so, um, yes but in the area of nice (.) yes I sach mal (...) homely has /mhm/. [...] Still, you don't feel like you're being watched. It's just the way you are, as you actually are during the visit, but you are a museum visitor. /mhm/ And um, yes, that's a bit of normality again." (C1-F3 PA-HS 56-57)

#### **REDISCOVERING AND UNCOVERING POSSIBILITIES FOR ACTION**

In addition to reopening up participation, the participants at the event "Art as Food" discover new, artistically oriented possibilities for action that they can also use at home. These new activities did not play a role in their lifes before, so that an expanded potential of possibilities for self-activity opens up here. Other participants experience the impulse or encouragement from the museum event to resume activities they pursued before the illness. There can be different reasons for abandoning them: one of them is the discouragement caused by the diagnosis and the prevention caused by medical treatment and its effects.

On the one hand, people's own artistic actions at home allow them to be distracted, and on the other hand, they are also an opportunity to deal with their own questions. Furthermore, they offer the opportunity to become visible with their potentials and to be able to communicate with others about them. These are factors that contribute to the quality of life and enable the experience of self-efficacy. In addition, the newly or rediscovered artistic spaces for action can provide support and encouragement in difficult situations of illness. In crisis situations, in which the self-experience of no longer being able to do anything can arise, artistic action is experienced as valuable, as it makes one's own abilities visible, which is described as strengthening self-confidence.

"B: Yes. Once this offer that you make (..) in connection with Mrs. Wiewrodt and all the others, (pause 6) that encourages me that it is not the end of the possibilities to enjoy art, but that I can pick up again. And also small steps to do it yourself." (G1-F3 PA-B 119-119)

"TN: () Again several times like this, that it contributes so much to the normalization of this museum visit () and then I thought, this is something special for me, well, before I'm not like that, I've never done something like that () which inspires me to design something myself and uh, that's why I think [ambient noise]() is maybe () [ambient noise] I can discover something new for myself, despite the illness, I can try something new, new skills." (G1-F3 GrD 55-55)

"TNw5: I've really talked about the visits here. About three years ago we were here for the first time () and that inspired me to become artistically active at home. And in a very bad phase of my illness, where I was completely (.) incapacitated by medication and seizures, I still created art. [Casually] TNm: mhmm. Terrific; TNw: That's good TNw5: (raises voice) To still have that when NOTHING else worked. That was unbelievably great. [Mumble TNw: I can imagine that] I: And that's what they discovered through the visits here TNw5: Yes, I've always been creative and I also like to draw well or something, but I've really rediscovered that here. I haven't painted or drawn anything for years and that's what I really did HERE. And during the illness and I had my second brain operation, because you can't read well with such a muddy brain, I just took a drawing pad and pencils with me and then I painted or drew without end (smiles). I sat in bed, freshly operated, and drawn. [murmur in agreement in the room] (G1-F1 GrD 82-93)

In everyday life, the participants experience that they are limited in their ability to act due to the tumor disease. In some cases, the assessment of whether these limitations are directly related to the tumor disease or whether they are personal limitations is blurred. If, for example, the experience is made in artistic practice during the event that, for example, filigree things and other challenges can be mastered to one's own satisfaction, then this is experienced as relieving and may strengthen the acceptance of one's illness. Another essential factor is that the intensive immersion of the participants in the artistic exploration has a deterring function, which leads to them being able to step out of their problem cycle during the event. The confrontation with the illness can temporarily fade into the background and it is not thought of for a while, as the person is focused on the artistic confrontation.

"Um, in the assumption of the illness once yes, because, um, I had, I think I had already started earlier in the direction, sometimes you don't know, for example, that is for example physical /mhm/ so (mobility?) that doesn't work or is that somehow um (.) something that the tumor might do /mhm/ and on the other hand, but when you work so filigree again, it's always an insane confirmation along the lines of: It's possible. That is, because often you just sit at home, take something in your hand, it just rattles. Um, but when you see, like last night I did again, with the paper cut /mhm/ um (..), you did it. That feels good. This feels really good, because it simply brings relief /mhm/ and all the time you don't really think about the disease / (G1-F3 PA-HS 16-16)

#### COPING WITH THE CURRENT LIFE SITUATION

The participants experience the museum visits as helpful in coping with their current life situation. The offer in the museum enables them to participate in a cultural event in a protected setting and to take their first steps into the public sphere. They feel at home in the group - especially through the sharing of a similar illness and the changes and challenges that come with it.

"And does that help you to be in such a special group in the museum? (..) Does that mean anything to you?-DB: Yes.- Which ones? (5s intermission) DB: Yes, that you don't feel alone and so lost, -SK: Hm.- that you (.) feel a bit in good hands and know that there are people who don't need to explain much, they all know that and (.) they have the same fears and the same things as you do and you don't have to talk about it much. -SK: Hm.- (G2-F3 PA-D 42-45)

The participants with brain tumors describe that the positive stories and the experience of an understanding encounter that they have with the other participants in the group remain in their memory for a long time and can be recalled on days when they are not in good health. If this succeeds, it gives them confidence and is helpful in overcoming the crises.

The perception of participants who courageously deal with the disease and live a bit of normality again serves as a role model for others and encourages them to find their own strategies to cope with the disease situation as well as possible.

If participants are perceived in the group who deal with the disease in a lifeaffirming way and seem to live a bit of "normality", this is experienced as a courageous approach to the tumor disease. These participants can become a kind of role model, which helps to release the numbness that has set in after the diagnosis and to find their own strategies for dealing with the disease situation in order to cope with it as well as possible.

"... yes, it also minimizes the fear when I see that others dare to do it. That I think, just as you are so anxious, others are freer (...) So yes, it also gave me such a deep shock to get this, yes this diagnosis, and (...) I thought I was going to die in the next few weeks, something like that" (TN-Interv\_PAB 203-206) "Of the other group participants, [.] [I] was also very impressed by how courageously some, (.) actually all, deal with their illness [], so that I thought: "Yes, good. You also have certain symptoms, and you have to see how you can best cope with them, but it's possible."

#### TAP INTO ENERGY RESERVES FOR EVERYDAY LIFE

If you take home your own works made in your artistic practice, they can act as a communication occasion to talk about them with friends, acquaintances or partners. This is perceived as helpful because, in addition to the value of communication, these conversations lead to them being able to remember their visit to the museum better.

The works taken home are thus artefacts that contribute to a more detailed memory of the museum visit. Sometimes the participants have the feeling of having the original works of art from the museum back in front of their eyes.

The opportunity to immerse oneself again in the memory of the event and the works in the museum is partly used as a strategy to be able to achieve a positive inner state on days of crisis. Based on the psychological state, certain works are sometimes consciously recalled.

# TRAINING OF COPING STRATEGIES BY RELATIVES ACCEPTANCE OF THE SITUATION

Through selected topics and works, the event encourages an examination of one's own life situation and one's own self. This encourages participants to continue to live their lives and embrace the condition.

The enthusiasm that arises during the visit to the museum is experienced as psychologically relieving and promotes the development of new perspectives on life, even if the partner is due for a new operation.

### EXPANDED PERSPECTIVE

To be able to exchange ideas with other relatives in the event and to learn that other relatives also experience the life situation and the changes in the partnership as challenging, is perceived as relieving and beneficial. If the relatives succeed in enjoying life despite the stressful situation, this shows them that it is possible to maintain a positive perspective and thus serves as orientation.

If the exchange between the relatives takes place in the course of the museum tour, this sometimes leads to an ambivalent feeling: talking to each other during the event is perceived as inappropriate on the one hand, but on the other hand there is a great need for it. In addition, the situation offers the freedom to do so, as the partner is involved in the leadership.

Strength is drawn from the perception of participants who seem to succeed in dealing with the disease. They encourage and convey confidence because they show that it is possible to cope with the disease situation and that the changed perspectives and ways of dealing with it can be found. A comparable family constellation of the participants, for example children of the same age, creates a special closeness.

During the reception, the artworks can be seen as a mirror for one's own, current and changeable life situation with a constant "up and down" and initiate an examination of it. In this context, the exchange on the works in the group is of particular importance, as the different perspectives on the works and in the transfer to the illness and the associated life situation become visible. The different perceptions of the other participants are spaces of possibility for one's own broadening of perspectives.

"FS: Yes (.) I always find it very bad when Mrs. Lauro tells something and others talk and yesterday it happened to me.

I: yes, well.

FS: It used to be, because, yes.

I: That was important, probably.

FS: That used to be important, yes. That was really good.

I: Yes (.) great. What was so good about it?

FS: Hm (.) she is also a relative and sometimes to hear that there is actually (.) um, yes, not everything runs as smoothly (.) as is always told by the patients themselves. (laughs) That's easy (.) did well (.) The fact that there is also (..) Yes, that there are also the (...) yes, quirks are there, changes are there, things don't work the way they used to.

I: Mhm.

FS: And with [Name1] and [Partner] it's like that, they still enjoy life, just like [Name2] does.

I: Mhm.

FS: And that felt good (.) there was another lady who is very depressed uh, we can't get her out of the hole, it's not our job either.

I: Mhm.

FS: But then it's good to find a couple who have the same problems and who are still doing well, like us (...) like that.

I: Ah yes.

FS: That's nice." (G1-F2 AN-S 23-37)

"how the pictures were interpreted, how much PLAYspace the art also offers, um, if I think of the (Pierrots?) think, um, what every single one of them saw there

I: Mhm

*S*: *uh these, these interpretations so I found that very interesting and yes it opens up, uh, just other possibilities, uh, to see things from a different angle, um,* 

I: What do you mean by that exactly?

S: Uh, yes um, if you apply that to diseases, um

I: Mhmh

S: I or you can certainly interpret it to the whole life, um, that you can really say, um, you can see a sad, a thoughtful person in a picture, a serious oh, oh, oh, see someone and so you can perhaps transfer it to the illness (.), that you say the one is completely devastated and MAYBE sinks with pity why I of all people (?) um. The next (.) for me is such a super positive example of the [name] (.), um, where I say with what kind of WILL of LIFE he goes there and gently "I just accept every day as a gift"

An: It's good to hear about the life situation of other relatives, to exchange ideas and to notice that other relatives have similar problems." (G1-F1 AN-Sun 23-33)

#### **OPENING UP TO PARTICIPATION**

For their relatives, too, the disease means that their lives revolve almost exclusively around the brain tumor disease. In addition to the inner conflict, worries and fears, the disease is also very time-bound. It requires, for example, the accompaniment of the partner or the organization of treatments and therapies. Leisure activities, attending cultural events, sports, etc. take a back seat or are no longer carried out by relatives at all. If the invitation to the museum event, which is issued as part of the psycho-oncological accompaniment, is accepted, the relatives experience that it is possible to do something beautiful despite the illness. Through the experience that a visit to the Picasso Museum is manageable, it encourages the relatives to undertake other activities such as visiting other museums or day trips together. The relatives assume that their participation in the event "Art as Food" at the Picasso Museum provided the decisive impetus for this.

"FS: ... such a diagnosis is already devastating (...) and then you arrive at home and then comes the whole therapy and (..) and you are only in this illness (...). Yes, and then you have the invitation to the museum (..), hm, well, then you go there (..) and see that there is something else (.). That's nice and (.) you did that, you did that in the group (.) oh then we can go to Münster somehow, or, well, you will, yes (.) you get self-confidence again. I: Mhm.

FS: Yes (.) In order to tackle other things, then you see, that were two hours, yes well, before afternoon nap, afterwards tired, exhausted (.) but well, it works, so we can also do something different here or we got this book from the [LWL Museum ?] and visited various museums also that we said: 'Come on, let's go on a day trip' (.) Yes, that's what we did (..) I don't know if we would have done it otherwise, I don't think so." G1-F3 AN-FS 154-161)

#### TAPPING INTO ENERGY RESERVES / CREATING POSITIVE MOMENTS

The visit to the museum is experienced by the relatives as sustainable. The intense impressions they get in the Picasso Museum, be it in their engagement with the works in the exhibition or in their own artistic practice, they take with them into their everyday lives, for example by being able to remember the works in pictures. Being able to remember the experiences and impressions made in the Picasso Museum at a later date is an enrichment for the relatives' everyday lives, as it can help to brighten their mood. It is experienced as relationship-strengthening when they can remember their visit to the museum together with their partner and exchange ideas about it.

The experience of artistic practice of having created something against all expectations is experienced as empowering and transferred as a positive experience into everyday life, in the sense that one can also create things that one would not have believed at first to be able to create or master.

The workpieces made in artistic practice are often taken home. In some cases, these are brought out from time to time, or they are placed in a visible place in the living room. When watched, they awaken memories of the museum experience, which is experienced as stabilizing. At the same time, the works created and taken away in artistic practice act as an anchor for positive feelings, which can also be evoked in everyday life by touching and looking at the objects.

I: Yes and you said so, you take the pictures home with you and (.) um (.) does that have an influence on your everyday life? FS: Yes. I: How. in what form?

FS: I did it last time, I did (break 5) [moving away from recording device] the first time it was, very proud, I've never done it.

I: Mhm (giggles).

FS: This pigeon recorded (.) [closer to the recorder again] I told myself, 'Well, you can do that, you can do that', I can tell you where this pigeon is hanging in the museum (.) and it's actually just lying around in the kitchen now. I: Mhm, but it's there.

FS: She's lying there, in this kitchen, and I'm moving it from one place to another because, no? It's also a bit bigger and every time I have this feeling, I'm standing in front of this picture (.) and I manage to draw this dove (..) this feeling is just inside me (.) I never thought I'd be able to do it. I: Mhm

FS: But I've made it and I'm so happy about it that I often think (.) 'Then I'll be able to do a lot of other things that I don't dare to do now'. (G1-F3 AN-FS 87-96)

FS: (laughs) Yes, you don't know, but man, so really this pigeon then, that was on the (..) eleventh of May I think, we were there in the Picasso Museum (..) yes, it has accompanied me over the time, right? Now that he was back in the hospital and stuff.

I: That means that what you're doing (.) actually accompanies you like a kind of power symbol here.

FS: Yes. (G1-F3 AT FS 171-173)

# SELF-CARE, ACTIVELY SEEKING HELP AND SUPPORT

The exchange with other relatives during the event at the Picasso Museum is experienced as positive. In order to be able to be in contact with other relatives

outside of the event, the participants arrange to meet each other, or they actively approach the psycho-oncologist with the desire to arrange contacts. Contacts with other relatives outside the event are considered important because they allow for mutual support. Despite having a functioning and large circle of friends and acquaintances, relatives often feel alone (abandoned) with the illness situation, because the circle of friends and acquaintances cannot well understand the peculiarities of the given life situation. Relatives use the psycho-oncologist's support in a targeted manner to actively and purposefully expand their social contacts and thus change their life situation in a positive way.

In addition, they use artistic practice in the event for informal consultation or to get rid of current problems. Here, relatives actively seek help and support from the psycho-oncologist and the art therapist as part of the event.

"... and in between I've been to Mrs. Wiewrodt again (..) and have also (.) ä::h her then asked, if she can't somehow n a little bit (.) make contact with other affected people [MG: mhm], with whom I sometimes feel, because I often feel quite alone with it, [MG: mhm] although I have many friends and many acquaintances, and they too, but none of them are affected [MG: mhm] and that's a good thing. But at the end of the day, if you have someone who feels the same way, (.) I think, then it's nicer (to help yourself then?) [MG: yes] (.) Yes and then I did, she also made contact with one, also affected and I think she was also, who warn in the first course [MG: mhm] (.) and with those, and she also comes to us from time to time (.) and we meet with them. (G2-F3 AN-S 5-5)

"... then a situation where a wife of a patient um(.) as, when her husband was just distracted, so to speak gently "I'll take the opportunity [laughing] and come to you" um and wanted to tell me uh just that he has such impulse outbursts, eh, that he seems so uh aggressive towards her as well, then apologizes again afterwards, but that she just has such a hard time taking it [M: Mh], she also started crying ..." (G1-F2 IV PO 11-11)

#### **S**AYING GOODBYE

The event "Art as Food" confronts the relatives, through the participation of the bereaved, with the possible death of their partner. The exchange and experience of the bereaved makes it possible to deal with the possibility of death and can still open up a space of hope.

Particular significance is attached to the works created in artistic practice by the affected relative. The partner's works are already seen as mementos in the present. In this case, the possible or imminent death of the partner is already dealt with in the current life situation. Dying is accepted as a possibility, which can open up an active confrontation with it. This is significant, as talking about dying is socially taboo and tends to be repressed.

"... although I then also found out, so uh next to me sat yes m::h the (.) somewhat younger gentleman [MG: mhm] the one to whom the woman also died and to the right of me (laughs) sat also one of the women, there the woman had also died (pulls up his nose and smacks) (..) but that didn't affect me at all, I always thought that "oouh" [MG: mhm] but not at all [MG: mhm] at all (.) so (.) and then I thought "life goes on, ne (?)" [MG: mhm] (..) even if the partner is no longer there (.) or so, if (...) and they are doing well (.) but (.) so (.) find, they are also so (.) so their all, live on their everyday life [MG: mhm] and (.) look (...) somewhere (...) so to get it (...) (and then I thought?) "Yes (.) if others can do it (...) then I can do it too" (G2-F3 AN-FS 15-15)

"... although I always find it very beautiful, these pictures that he takes, where he (.) has actually always said that he is a gross motor expert and that he has nothing to do with art.

I: Mhm.

FS: They're always great.

I: That's it.

FS: With a few brush strokes, I can get you another one from over there right now (laughs) (.) uh, he has an expressive picture and I think that's nice, because that will stay (.) from him (laughs) (..) when he will no longer be there. No?" (G1-F2 TO FS 124-128)

# TRAINING OF COPING STRATEGIES BY THE BEREAVED

Since the benefits for the surviving dependents were not initially the focus of the study, we will only summarize the effects for the bereaved in this article.

# **PROCESSING GRIEF**

For the bereaved, the intensive exchange of information about their own life situation with other bereaved relatives is significant. It creates a mutually reinforcing, trusting level, which sometimes also leads to appointments outside the museum. The bereaved families say that the comprehensive, reciprocal exchange, even outside the museum, contributes to coping with the loss and promotes a positive attitude towards life. Bereaved relatives also assume that the examination of the works in the museum space as well as their own artistic practice as well as the discussions in the group have an important function in saying goodbye and in processing the grief. There are also participants who see the event as an important support, but assume that the pain will never subside. It is emphasized by the bereaved that it was important for them to be allowed to continue to participate in the event after the death of their partner.

#### **C**HANGE OF PERSPECTIVE

The museum visits are seen by the bereaved as part of the overall support system that helps them to come to terms with their own situation and to be able to develop a positive attitude towards life again. For this, one's own motivation to want to change something is important. The extent to which the museum event influences them is not reflected by the bereaved. The entire support system they use contributes to a changed perspective on life.

#### (RE) DISCOVER SPACES FOR ACTION

In the artistic practice in the museum, the bereaved experience new and unconventional solutions. This experience is partly transferred to everyday life.

Motivated by the experiences at the Picasso Museum, bereaved relatives also begin to be artistically active at home, which they would not have done without this experience. In order to initiate independent artistic activity in one's own living environment, one or two museum visits are sometimes sufficient. Artistic action at home takes place in an exploratory approach, is joyfully experienced and opens up previously unknown spaces for confrontation.

The guided tour of the Picasso Museum as part of the event "Art as Food" triggers the impulse to deal with art outside the framework of the event, which is experienced as helpful. The bereaved also go to other museums, read books on art, etc. In this way, the event has an influence on leisure behaviour.

#### **DISSOLVE NUMBING**

The event is seen as a help and perceived as beneficial, although the confrontation with the other participants and their medical histories is sometimes a burden. These sometimes triggers of painful hours are seen as a challenge. The successful encounter with the disease of the participants with brain tumor as well as with the relatives is considered helpful and conveys one's own, regained strength to

be able to face this encounter. In the transcript, the bereaved also dare to go back to places or events that were previously visited with the deceased partner and were rather avoided after death and now enjoy this by themselves.

After the death of the partner, it is not uncommon to occur a withdrawal from the social environment, and there is little motivation to act. In artistic activity at home, which was initiated by the "Art as Food" event visits, the bereaved open up to a new field of action that gives them joy and enables them to deepen their knowledge. They find peace in artistic action and experience themselves as competent to act. One's own artistic activity in one's own home is seen as helpful in coming to terms with the death of one's loved one.

The discussions in the group enable the bereaved to perceive that other bereaved relatives are able to continue living despite the given situation. In addition, they learn how diverse and individual life after the death of a partner looks like and also that one can succeed. This encourages the bereaved to take back control of life. It gives them the feeling that it is "allowed" to do something beautiful and joyful again. The group can also convey the feeling of not being alone in the situation.

#### WANTING TO HELP

Individual bereaved relatives develop the need to be of help to the other participants in the group. They assume that, based on the experiences they have made, they will be able to help others in coping with the illness situation and in difficult life situations.

#### **FINAL THOUGHTS**

The qualitative findings *gained in the course* of the study clearly show that participants with brain tumors benefit significantly from the event "Art as a Means of Life". On the one hand, because the visit immediately relieves them by allowing them to step out of crisis mode for a while at the Kunstmuseum Pablo Picasso Münster, and on the other hand, because at the same time they can enter into an exchange with the other participants that strengthens them. In this regard, Reuter and Spiegel explicitly point out the positive aspects of therapeutic group offers for

# cancer patients. In particular, the authors emphasize the importance of homogeneous groups with regard to tumor type, as was the case in this study<sup>23</sup>.

"Cancer patients often suffer from both existential isolation and feelings of loneliness that occur in relationships. Here, it is a therapeutic task, on the one hand, to make a new sense of connectedness tangible in the group and through the group, and on the other hand, to work with those affected towards the possibility of new encounters and moments of human connection"<sup>24</sup>.

With regard to the research question, it can be emphasized that brain tumor patients are supported by participation in developing individual coping strategies. The same applies to the relatives and the surviving dependents. Thus, the offer "Art as a means of life" is an important element of psycho-oncological support and can be well integrated into it, also because it is possible to take up and continue the experience gained in the museum in therapeutic support in the clinic.

With regard to the general conditions, it therefore seems sensible that the psycho-oncologist, as well as the art therapist integrated into the treatment, regularly participate in the events. This allows participants to seek support on an informal level or to relieve themselves. Another aspect not presented in the text, but which is evident in the interviews of the participants, is that the participation of the therapists is experienced as appreciation and also underlines the importance of the offer.

Furthermore, it has been shown that the joint participation of brain tumor patients with their relatives makes sense. There are indications that joint participation helps to integrate the transfer of the experience gained in the museum into everyday life. This aspect is an indication that "active creation of meaning"<sup>25</sup> is made possible by participation in the art-based offering. "Yalom<sup>26</sup> distinguishes between a *meaning in life* and the *meaning of life*. Both are important aspects for clinical work with cancer patients, with an often smooth transition. The meaning of life presents itself as a meta-meaning that often springs from religious or spiritual ideas and experiences. In the confrontation with finiteness, the question of the

<sup>&</sup>lt;sup>23</sup> Reuter, Katrin; Spiegel, David: Psychische Belastungen bei Krebserkrankungen. Gruppentherapie nach dem supportiv-expressiven Ansatz., Göttingen, 2016, Hogrefe, p. 41.

<sup>&</sup>lt;sup>24</sup> Ibidem, p. 74.

<sup>&</sup>lt;sup>25</sup> Ib., p. 75.

<sup>&</sup>lt;sup>26</sup> Irvin Yalom, born June 13, 1931 in Washington, D.C.. American psychoanalyst, psychotherapist, psychiatrist and writer.

meaning of life after death arises from this. The *meaning of life*, on the other hand, is connected with *earthly questions* and requires commitment and obligations"<sup>27</sup>.

Through the receptive and active art-based interventions, the supportive offer in the museum provides patients, relatives and bereaved families a multilayered and protective field of practice in which the participants can experience themselves as competent and creative in artistic practice. The complex overall effect of space, artwork, mediation, relationship formation and sensual perception and action contributes to the stabilization of the feeling of coherence, in the sense of comprehensibility, manageability and meaningfulness (cf. Antonowsky 1997).

"Life is still beautiful because you see it very differently than it was before. /mhm/ And you just have to get involved with it and that's just (.) a lot, I guess a lot. This view is also due to the meeting in the museum, the visits and the conversations." (G1-F3\_PA-HS 60-60).

The quote from a participant once again underlines the potential of the event to change the quality of life of patients, relatives and bereaved families in a positive way.

In addition, the series of events planned throughout the year at the museum structures the calendar with a monthly jour fixe, thus offering a temporal goal that patients and relatives can focus on and look forward to.

Overall, the findings are very encouraging and should motivate clinics and museums to develop similar offerings.

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<sup>&</sup>lt;sup>27</sup> Reuter, Spiegel, op. cit., p. 75

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