

Facing fears, facing opportunities:

Lessons learned from a participatory design format with people affected by social anxiety

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ABSTRACT

Social anxiety disorder (SAD) is one of the most commonly diagnosed anxiety disorders and a health concern that has a significant impact on the affected individuals' quality of life. Although there is a need to develop methods and tools to support those affected by SAD, it is especially challenging to conduct participatory design with this psychologically vulnerable group of people. This paper presents the design, implementation and evaluation of a participatory format built on a toolkit, a cultural probe and an online prototyping workshop to gain insights into the challenges and needs experienced in the everyday lives of those affected by severe social anxiety. We provide the theoretical framework for designing a participatory format for this vulnerable group, introduce and discuss our methodological approach, and present the lessons learned from implementing and evaluating the format in two workshop sessions with a total of 15 participants.

Keywords: Interaction design process and methods, Participatory Design, Social Anxiety, Prototyping, Toolkits, Online Workshop

1 INTRODUCTION

Anxiety is a fundamental human emotion that helps us to recognize dangerous situations. Perceptions of physical or psychological danger cause our minds and bodies to react. However, anxiety can become pathological when anxious behavioral responses persist in everyday interactions and thus result in people consciously avoiding particular situations out of fear. With an approximate 12-month prevalence rate of 2.7% in the German population, social anxiety disorder (SAD) is one of the most common psychological disorders and represents a significant health concern [19]. Researchers even expect that the number of individuals suffering from mental disorders, such as SAD, could increase as a result of the COVID-19 pandemic [52]. Reduced exposure to social situations could lead to the

maintenance of social anxiety[4]. These circumstances and recent developments highlight the urgent need to develop ways to support people affected by SAD in re-engaging or reconnecting with society.

Nonetheless, it is particularly challenging to implement participatory design formats with this psychologically vulnerable group. SAD is characterized by an excessive fear of being exposed to the scrutiny and negative evaluations of others in social contexts. Those affected experience social or performance situations as severely stressful and tend to avoid them altogether [2]. Therefore, people affected by social anxiety have high inhibition thresholds for participating in such (social) formats, thereby creating the following challenge: How can a participatory format be realized for people affected by SAD, for whom workshop formats per se represent a significant burden? To address this challenge, we adopted a practice-based exploratory approach to investigate how tactics commonly used in design—from reflective methods to making practices—can be adapted and implemented to support participants in communicating needs, visions, and (tacit) knowledge of their psychological condition.

In this paper, we present a theoretical outline based on the state of the art in design research, human-computer interaction (HCI), and psychology. We examine the potential of physical prototyping as a co-creating approach and elaborate on the specific challenges experienced in participatory design formats by those affected by SAD.

We show a hands-on example, introducing our participatory format, which consists of three parts: 1) a cultural probe to prepare for the workshop, 2) an online co-creation workshop built on prototyping activities, and 3) a post-workshop (self-)observation. We discuss the design, implementation, conduction, and evaluation of this format, which we administered conducted with 15 individuals experiencing intense feelings of social anxiety. The aim of the format was to create a space for trustful exchanges to gain insights into the participants' needs and coping strategies regarding their psychological illness. Finally, we present what we learned from our practice and the evaluations of the workshop participants to provide recommendations for action and further research. The purpose of this paper is to provide insights into our work and to contribute to the discussion on ways to conduct appropriate participatory workshops with and for psychologically vulnerable groups.

2 BACKGROUND AND RELATED WORK

The specific requirements arising from the psychological vulnerability of people with SAD make the implementation of participatory design with this social group particularly challenging. In the following section, we provide theoretical background concerning the challenges participation presents for people with SAD. We also provide an overview of current discourses and approaches around participatory design and prototyping in the field of mental health.

2.1 Challenges for participatory design with people affected by social anxiety

Participatory design, especially co-creating with target groups (we use the term "co-creation," as defined by Sanders et al., to refer to "any act of collective creativity" [42]), has become a relevant mode in design and HCI practice as a way to include the multiple perspectives of these groups. The approach considers participants to be both partners and experts in the design process. Compared to user-centered design, participatory design aims at incorporating a higher degree of user participation in the design process: Instead of designing for people, the paradigm has shifted towards designing with people [10]. In addition to ethical considerations, projects have been proven to be less likely to fail when solutions are developed together with end-users [35]. However, a few concerns must be addressed, especially when working with vulnerable groups. Following Bødker and Kyng [9], participatory

design often implies here-and-now co-creation and not the building of long-term relationships. Vines et al. [49] highlight the importance of developing caring relationships with participants from vulnerable groups, arguing that such relationships build trust and help researchers better understand the person aside from their (mental) illness.

In a participatory context, individuals with SAD must be considered a highly vulnerable group for several reasons. SAD is more often related to comorbid psychological disorders than other chronic psychiatric disorders along with more significant impairments in social functioning [21]. For people affected by severe social anxiety, sharing experiences or feelings with a high level of intimacy is extremely likely to be associated with the fear of disapproval [29]. They tend to engage in self-criticism [18] and fear evaluations of all kinds [50]. Moreover, individuals affected by SAD have an increased risk of panic attacks in social situations [22]. As a result, a particularly sensitive approach is required in a participatory context. It is therefore essential to consider the specific needs of people with SAD when developing a participatory format. Generally, performance situations that require creativity have a higher probability of inducing anxiety than other performance situations [11]. Ensuring the design task consists of a small work load [34] and a humorous approach could therefore contribute to maintaining a tolerable stress level and foster design creativity [30][1][16].

Within the participatory design community, a large body of work exists on participatory design approaches with vulnerable groups. These groups are diverse and differ significantly in terms of needs and challenges. Within the field of psychologically vulnerable groups, research is being conducted on participatory design formats for those living with dementia [32], intellectual disabilities [36], autism [45], or depression and anxiety [20]. Only a few studies have reported on experiences with participatory formats with individuals affected by social anxiety. Bertelsen et al. [5] discuss the challenges associated with co-creating mobile support for cognitive behavioral therapy-based anxiety treatment with people suffering from either social anxiety or agoraphobia and their therapists. They describe how engaging users with anxiety in participatory design is particularly challenging. However, other well-examined contexts exist in which people with SAD have entered group settings. One of these settings is cognitive group psychotherapy, which leads to increased group cohesion [46].

Building on the different perspectives described above, we consider group settings and thus participatory formats to be feasible, acceptable, and profitable for people with SAD if they are sensitively designed and tailored to their needs.

2.2 Prototyping and co-creation practices in participatory design

Participatory research to co-create knowledge and inform action is well established in health research [39]. While often implemented in the form of consultations such as focus groups, Langley et al. [26] propose a more hands-on approach for activating, mobilizing, and sharing knowledge in healthcare through co-creating and the act of "collective making." Prototyping in participatory design often serves to co-create possible solutions with representatives of the target group. As an example, Simm et al. [45] conducted workshops with adults affected by autism and their caregivers to build and test the potential of individual DIY prototypes for the self-management of anxiety. Prototyping for ideation is based on the creative potential that lies in the act of "thinking through prototyping," hence, it involves interacting with materials in comparison to just thinking things through [24]. The idea itself emerges or is further developed through the process of representation [15].

In health-related participatory design research, prototyping also offers the potential to explore inquiry spaces, such as the challenges and needs of given target groups [12]. Other researchers have used prototyping activities to externalize (bodily-) feelings to communicate highly individualized accompaniments to health impairments, such

as the perceived discomfort and pain accompanying a migraine [6]. Experience and knowledge are often tacit and difficult to put into words [38]. Prototyping is a means to grasp tacit knowledge, allowing participants to explore, reflect, express, and share their everyday experiences and needs in an embodied way directly through the process of making [44].

Further studies address the uncovering and strengthening of resources, sufficiency practices, and self-empowerment through designerly tools in participatory settings with vulnerable groups. Munro [31] outlines the value of an "appreciative co-design" that departs from the widespread problem-solving mindset toward identifying strengths and supporting self-empowerment through externalization. Externalization aims at "encouraging participants to detach from their identity as problem owner" (e.g., from "I am depressed" to "the depression"). This approach builds on White and Epton [51], who agree that framing the problem as a separate entity, that is, as an external representation—for example, a physical object—allows individuals to observe the problem from an objective distance and, through this, identify strengths.

Prototypes and self-created artifacts can also enable communication among people of different backgrounds, professions, and levels of expertise [26] as they facilitate the different participants articulating and sharing their expertise [48] and building a shared understanding [23]. Prototypes do not necessarily communicate ideas or thoughts explicitly, but they can be, intentionally or not, metaphorically encoded [37]. Through descriptions of and discussions about the artifacts with participants, underlying needs can be decoded. Ambiguity is a resource for the communicative role of prototypes as it gives rise to multiple interpretations [13]. Low-fidelity (lo-fi) prototypes, as ambiguous artifacts, therefore, encourage elaborative dialogue and creativity [28].

Within this context, experimental tactics such as open-ended making and the use of fiction foster conversations in an accessible form and stimulate imagination and participation. Open-ended making engages workshop participants in imagining and crafting novel things that are fictional but "expose underlying personal desires as drivers for ideas" [3]. The shift toward pushing ideation beyond the constraints of solutionism and technical feasibility has been adopted by a growing body of related research. The research proposes that fictional and other experimental approaches and practices such as design fiction [7] [25] or anti-solutionist making [47] [27] [8] are valuable resources for design research and HCI to engage debate and open new perspectives. Through the staging of fictional scenarios, some approaches demonstrate how the use of fiction encourages participation [25]. Other researchers agree that using design fiction in participatory design processes enables vulnerable individuals to observe their reality from an unusual perspective, making it easier for them to speak about their concerns and reveal their values, needs, and imaginaries [33]. Experimental approaches also adopt humor, irony, or satire as stylistic devices to enable a cheerful and low-threshold atmosphere while approaching complex topics, eliciting self-reflection and critical thinking, and enabling discussion [47] [27].

2.3 Cultural probes and toolkits

One way to facilitate participation in design research is to create and provide tools for participants, such as "cultural probes" [14] or toolkits [43]. In contrast to formal and language-based questionnaires, cultural probes attempt to generate an enjoyable and creative inquiry. Cultural probes may combine diaries, workbooks, postcards, cameras, or games, among others, and include a range of methods such as drawing, storytelling, or prototyping for gathering data about people's everyday lives. With their personal and informal qualities, cultural probes aim to reveal emotions, expectations, and beliefs [14].

"Generative toolkits" [40], in contrast, facilitate participants taking on the co-designer role even if they have little experience in creative making. Toolkit components can consist of various (mostly simple and familiar) materials. "Constructive assemblies" in particular [23]—tangible, reconfigurable, modular physical sets—ensure the skill barrier is low. Following the authors, social inclusion is fostered by lo-fi prototyping that does not require design experience. Furthermore, constraint through material selection can lead to more expressive and creative use. In online-led co-creation formats, a shared toolkit can compensate for some of the limitations of decentralized collaboration [23]. This point is of particular interest as the discussion around the potential and limitations of online participatory formats gained relevance due to the contact restrictions during the COVID-19 pandemic. Sanders et al. [23, 41] stated that participatory design sessions should preferably be held face-to-face, as online sessions do not allow tools and methods to reach their full potential. However, Khan and Matthews [23] demonstrated that participatory design sessions can be successfully conducted as online sessions with the help of shared toolkits.

3 PARTICIPATORY FORMAT

We developed a participatory format explicitly tailored to the needs of people affected by social anxiety. Workshops, as performative social situations, were expected to be especially challenging and potentially stressful for people suffering from social anxiety. Therefore, it was necessary to design the participatory format very carefully to enable their participation. The aim of the format was to learn from the personal experiences, needs, coping strategies, and challenging daily life situations of people with SAD. The knowledge acquired establishes the basis for further stages of our design process and grounds the development of technology-based solutions that could support individuals in coping with fearful situations in their everyday lives.

3.1 Workshop design

The developed participatory format contains three parts: 1) a cultural probe, which should be completed in preparation for the workshop; 2) an online co-design workshop with a prototyping session and discussions mediated by the crafted artifacts; and 3) a post-workshop (self-)observation, which involves a (fictional) evaluation of the crafted ideas in everyday life situations. The format was facilitated by a toolkit that was sent to participants in advance of the workshop. It contained a booklet and a box with materials for the prototyping activities. Prototyping was an integral part of the methodology for the cultural probe and the online workshop. First, prototyping was intended to support self-reflection in an embodied form through confrontation with the materials. Second, the resulting tangible objects aimed to facilitate access to and communication of (tacit) knowledge.



Figure 1: The toolkit including the workshop booklet, the cultural probe and prototyping material (left). The cultural probe (middle). The prototyping material (right)

To meet the needs of the target group, the toolkit was designed to provide a low-threshold entry point into creative processes. Providing the opportunity to assemble materials rather than forcing people into a craft process (such as drawing or making) was intended to break down barriers and avoid feelings of "cannot do" or fear that the result will be "ugly" and insufficient.

3.2 Workshop booklet

The booklet guided the participants through the entire process and contained all the information, guidance, and instructions necessary for each of the three parts. Specific language and phrasing were chosen to build an open, positive, and empowering mindset. Central emphasis was given to the expertise of the participants, thereby conveying self-efficacy. The workshop's intentions and schedule were described in step-by-step detail to provide orientation and confidence and thus satisfy the participants' need for control. Tasks were explained in detail, and their underlying purpose was communicated transparently. Contacts for further inquiries were also named.

3.3 Part 1: Cultural probe

The first chapter of the workshop booklet contained a cultural probe designed to help participants prepare for the workshop and to provide the project team with valuable information about the participants' different fears, anxiety levels, and individual strategies for dealing with their fear. Questions and tasks were set in a way that, if possible, created an atmosphere in which serious topics could be addressed in a light and humorous manner. The intention of this was to create a helpful distance from the topics, and this change of perspective also aimed at stimulating free and creative thinking, thus, leading to more unconventional ideas. The booklet contained cheerful and humorous illustrations to foster a positive and stimulating atmosphere. As an example, fear was personalized as "Angus," an anxiety mascot. Moreover, the illustrated "superpowers" were intended to raise people's awareness of their own resources in a humorous way (Figure 1, middle).

In one task, participants were asked to physically represent their fear as a type of mascot by combining a selection of materials provided in the toolkit. The physical creation of this anxiety mascot served to express tacit knowledge and was intended to create some helpful distance from the participant's own condition and symptoms by presenting the problem as an external representation. The associative and haptic work with materials was meant to offer a more intuitive and playful way to express thoughts and feelings. The aim of the task was to learn more about the participants' individually felt fears, for example, how they experience fear and the situations in which it occurs. Moreover, introducing prototyping activities in this early workshop phase was also considered helpful for increasing the participants' familiarity and confidence with the task in preparation for the online workshop.

3.4 Part 2: Online co-creation workshop with prototyping activities

A central aspect of the online workshop was a co-creation activity based on prototyping. Due to the COVID-19 pandemic, the workshop had to be planned and implemented in an online format. All the necessary materials— included in the toolkit—were sent to the participants in advance. The online workshop was conducted via the Zoom videoconferencing platform.

To create a pleasant workshop atmosphere and a good group climate, welcoming and getting to know each other played an important role. In this context, the prototyping materials of the toolkit were used as conversation starters; everyone present—both participants and team members—briefly introduced themselves and described a material they found exciting. Later in the workshop, the toolkit materials were used for a short relaxation session to reduce anxiety: In a "sensorial journey," participants were encouraged to explore the materials with their hands, experiencing the different haptic qualities. This activity also sought to consciously address and sharpen various senses to facilitate the development of exciting and multisensory enriched ideas. This activity was followed by the main task of the online workshop. The participants were asked to use the toolkit materials to visualize their ideas and visions concerning support for managing their social anxiety. The ideas were documented in a fact sheet, which provided the participants with guidance for a short presentation of their ideas to the group.

For all the activities, especially those concerning ideation and prototyping, we adopted a fictional and anti-solutionist approach to enable participants to address complex aspects from a different angle. Although we did not explicitly include the creation of design fictions or anti-solutionist making, we embraced the mindset behind these practices. We engaged participants in crafting artifacts and scenarios unlimited by constraints such as known facts or feasibilities. Using fiction as a resource, the primary aim of our approach was not to craft ready-made solutions to their problems. Rather, the aim was to provide a low-threshold space for externalizing underlying needs and coping strategies and to open new perspectives toward novel design and technologically mediated opportunities.

The materials provided in the toolkit were intentionally kept as simple and unprepared as possible to leave space for creative expression and metaphorical encoding when creating the artifacts. The focus was not on artistic qualities but rather on what was communicated either in the process of making the artifact or in the description of the artifact afterward. At the end of the prototyping session, the participants were asked to present their objects to the group and the facilitators to tap into the artifacts' inherent meanings, ideas, and knowledge. Furthermore, the presentations were intended as a starting point for a group discussion with the participants.

3.5 Self-observation

The third phase of the participatory format engaged the participants in taking the crafted artifact with them for a few days after the workshop and observing its use in everyday life. Participants were asked to complete an observation table describing the situation, prevailing feelings or thoughts, and potential support from and further development of their ideas.

4 IMPLEMENTATION

4.1 Recruitment and data protection

Potential participants were recruited through a German self-help organization for people affected by a SAD called Federal Association for Self-Help Social Phobia e.V. (Bundesverband für Selbsthilfe Soziale Phobie e.V.). Eligibility criteria included 1) being 18 years or older, 2) being affected by SAD or subthreshold SAD, and 3) being in a stable

psychological condition. The latter was determined before the workshop by the psychotherapist in the team. Participants were informed about the use of the collected data and the regulations for maintaining confidentiality following GDPR standards. Sensitive data were anonymized, and only members of the research group had access to the encrypted data.

4.2 Participants

A total of 15 participants were recruited for the workshop. In order to create an atmosphere suitable for the group's needs (e.g., to prevent fears associated with large group sizes), two dates for the prototyping workshop were offered. Six participants attended the workshop on the first date, and nine on the second date. One participant dropped out during the first online prototyping session due to a high distress level. The final sample consisted of five women and 10 men (self-reported gender) between 20 and 57 years of age and from different cities and rural areas in Germany. A larger number of women and other genders would have been helpful to create greater gender diversity within the sample. In order to avoid placing the participants under additional pressure, they were not asked about their education, current work situation, or whether they were currently undergoing psychotherapeutic or psychiatric treatment. All participants reported suffering from SAD, although no proof of diagnosis was required. However, participants were asked about their psychological resilience and were supervised by the team psychologist before and after the workshop.

4.3 Relationship development and psychological accompaniment

From the beginning of the recruitment process, we paid particular attention to building a bond with the participants to reduce their fears of the workshop and encourage them to participate. This care included regular email contact, through which we communicated information about the state of planning and preliminary information about the workshop schedule and goal.

Our workshop concept was explicitly not a psychotherapeutic offer, which we openly communicated to the participants. Nevertheless, addressing anxiety and one's feelings and emotions in the context of the workshop presents the risk of causing high distress levels. Therefore, the project team and workshop leaders had to be able to manage acute situations of distress. In our case, a psychological psychotherapist was part of the project team and provided psychological support for the workshops.

4.4 Procedure

The workshop toolkits were sent out to allow the participants at least one week to fill them out before the online workshop. A prepaid return label was included in the package so the participants could easily return the completed booklets. The online workshop was conducted with the two participant groups on two days (12/12/2020 and 19/12/2020). Both sessions followed the same structure and procedure. Four project team members participated in each online workshop: a psychotherapist, two designers, and an information scientist. The planned duration of the workshop was 2.5 hours. Both workshop sessions were scheduled on Saturdays to make them compatible with the participants' daily (work) schedules. Consistent with the exploratory nature of our approach, minor adjustments were integrated into the second workshop from the learnings of the first online workshop. Due to some participants experiencing technical difficulties with sound and video in the first session, we provided an illustrated overview of the essential Zoom functions and offered optional individual appointments via video calls for software and hardware tests before the second session.

Participants were asked to return the workshop booklet after completing the workshop and the self-observation activities. Twelve out of the 15 booklets were returned. Following the workshop, the participants were asked to take part in an anonymous online survey to evaluate the format.

The created artifacts were photographed and provided to the research group by the participants. The completed workshop booklets were digitized for further analysis. In addition, the workshop audio recordings were transcribed and pseudonymized. All data material was uploaded into the qualitative data analysis software MAXQDA-20 and analyzed using content analysis to find phenomena and patterns within the data. Both inductive and deductive coding were used. The analyses of the material will be published as soon as possible, as deeper insights into the workshop analysis cannot be provided within the scope of this paper. The goal of the present paper is to highlight the lessons learned from conducting a workshop of this nature.

5 PARTICIPANT EVALUATIONS

Through an anonymous follow-up online survey, we approached the participants to obtain feedback to improve the co-creation workshop based on the inferences of the group being studied. All 15 workshop participants completed the survey. The survey consisted of a mix of close- and open-ended questions. Eighteen close-ended questions were included to evaluate the workshop's personal benefits and feasibility. Fourteen open-ended questions served to gather recommendations for improvements for future workshops.

As described in section 4.3, we were in close contact with the participants before the co-creation workshop to build trusting relationships. Most participants (8) stated that the close contact motivated them to participate in the workshop.

In advance of the actual workshop, a booklet was sent to the participants (see section 3.3). Most of the participants (8) rated the booklet as helpful. Completing the tasks and questionnaires in the booklet made it easier for them to prepare for the workshop. For example, one participant described the benefits of working with the booklet as follows: *"For me it was very good to work with the booklet in advance to have a more concrete idea of what would happen in the workshop. That calmed my fears a little. I had lots of fun creating my anxiety mascot and, thus, thinking about my own anxiety."* *

The task of creating an anxiety mascot from the materials provided was considered helpful by most participants (9). They indicated that this task taught them something new about their anxiety or helped them to communicate their feelings and thoughts. Nevertheless, three participants shared that they felt pressured when completing the tasks. One participant stated, *"It put me under a little pressure because unfortunately I am not very creative, and it was completely new for me to do something like that. It was of some help that the mascot didn't have to be 'pretty'."* *

Three participants would have preferred another approach to prepare for the workshop, such as a questionnaire or interviews. Our tactic of taking a humorous approach to the materials (see section 3.3) was generally welcomed, and most participants (8) stated that completing the tasks was facilitated because of the informal style of the booklet. More precisely, they could observe the issue of their anxieties from a helpful distance and learn something new about their anxiety. However, while most participants (8) found the humorous approach self-enhancing, two participants felt they were not taken seriously.

Regarding the fact that we had to conceptualize the workshop online via Zoom, opinions about the online format ranged from ambivalent to critical. Two participants were very positive about the online format, stating they felt more secure and safe working from home. Moreover, they highlighted their decreased anxiety levels and the possibility of working in a calm environment as specific advantages of working online. However, three participants

expressed ambivalence: They endorsed the positive aspects mentioned above but, at the same time, expressed negative concerns. Four participants reported experiencing disadvantages due to the online format. Specifically, they reported experiencing stronger feelings of insecurity, a lack of group feeling, or technical difficulties. Half of the participants (7) would have preferred a face-to-face workshop format. In accordance with many other participants, one participant communicated mixed feelings about the situation: *“I find it difficult to know what’s easier for me. Face-to-face is probably associated with even more anxiety. But that’s also present online. In face-to-face there is more development of team spirit and more exchanges, though, I think.”**

Along with the online workshop, we offered appointments for a soft- and hardware test prior to the workshop (see section 4.3). Most participants (8) felt that the offer was not necessary.

Regarding the workshop duration (see section 4.4), most participants (7) stated that 2.5 hours felt appropriate. Four participants felt the format was slightly too long. According to the group size, all the participants in the first group (six participants) found the group size pleasant. However, two participants in the larger group (nine participants) shared that they would have preferred a smaller sized group.

The tasks set in the online workshop were sometimes unclear to the participants. Most participants (7) stated they had problems understanding or following the workshop tasks, primarily because of too much stress caused by their social anxiety (six participants).

The prototyping activities in the cultural probe, as well as during the online workshop with the given materials (see section 3.3 and 3.4), were evaluated positively by most participants (9). Among other things, they described the process as inspiring and motivating. In the case of the online workshop, the prototyping task was described as helpful (seven participants) and fun (eight participants). Participants stated that working with the material helped them to make their ideas and thoughts tangible and to communicate them.

The presentation of the created artifacts (see section 3.4) was described as positive or inspiring by most participants (7). However, some (3) had difficulties with presenting their objects because they felt shame, they were afraid of the large number of people listening, and they knew their words were being recorded. Some participants even stated that simply knowing that the artifacts had to be presented hindered their creative workflow in the prototyping session. In this context, one participant stated, *“At the beginning, I again found it very difficult to get involved. Additionally, the social anxiety prevented me from thinking creatively. Because I had the thought I have to do something perfect. All the others are doing something that’s better.”**

Further, some participants (5) wished for more discussion with the other participants or the moderators.

The self-observation that occurred after the workshop (see section 3.5) was evaluated remarkably differently by the participants. Six participants stated that they had benefited from it. Among other things, the self-observation helped them review and further develop ideas or gain new insights into anxiety coping strategies. Six participants stated that they had experienced problems with self-observation. Specifically, the problems mentioned were the large amount of time required, problems understanding the task, and emotional stress.

In summary, overall the workshop was evaluated positively by the participants. The workshop design and implementation concept were appropriate for the target group.

*All quotes are from anonymous participants and were translated from German into English by members of the project team.

6 DISCUSSION AND LESSONS LEARNED

To analyze our approach and the workshop design in terms of our predefined objectives, in this section, we discuss the results of the participant evaluations in relation to the literature and our findings from the workshop implementation and outline our "lessons learned."

6.1 Relationship building and social support

Prior to the workshops, the psychotherapist in our research team was in close contact with the participants through emails and phone calls. This procedure is rather uncommon for research studies in order to avoid bias, for example, due to social desirability. However, in our workshop approach, **pre-workshop bonding proved crucial to creating a personal bond and a trusting atmosphere in advance**, leading to a low dropout rate (with no dropouts before the online workshop) and providing participants with the confidence and motivation they needed to overcome their fears of participating in such formats. This aspect is in line with Vines et al. [49], who stated that building a trusting relationship with vulnerable individuals is crucial for successful participatory processes. To ensure meaningful and healthy engagement and participation, it is essential that the participants feel safe and supported during the whole process. To this end, and due to the high vulnerability levels of those affected by SAD [22] [21], **constant and consistent psychological accompaniment is required for the workshop when coping with fearful situations and emotional challenges**. Moreover, we found that the project team also obtained clear benefits from integrating psychological supervision. Obtaining information, feedback, and support from **a psychologically trained person helped to provide an atmosphere that was characterized by mutual respect and understanding**.

6.2 Humor as a resource

Specific language and phrasing were chosen to build an open, positive, and empowering mindset to create an atmosphere in which serious topics could be addressed in a light and humorous manner. Humor plays an essential role in the appraisal of stress and the application of coping strategies [1] [16]. In this sense, a light and benevolently humorous approach was considered conducive to the workshop, which the results of the participant evaluations confirmed. **Respectful humor helps in facing serious topics and is a possible way to facilitate an informal and non-problematizing setting**. However, since people can feel that they are not being taken seriously in a humorous approach, it is crucial to ensure that the level of humor is appropriate for the topic.

6.3 Workshop booklet and cultural probe

The aim of the workshop booklet was to guide the participants through the entire process of the participatory format. **Transparently communicating detailed information about the workshop goals and procedure in advance proved very helpful**, as it contributed to fulfilling the participants' need for safety and control.

One main goal of the cultural probes was to learn about the participants' social fears. The tasks were completed in detail by the participants and provided valuable information, which included anxiety situations and triggers, and individual strategies for coping with anxiety. These highly personal and meaningful results support those of Gaver et al. [14]. They found that participants tended to communicate in a personal way when working with informally and personally designed cultural probes. In addition to the valuable insights they provided in terms of user research, **providing the cultural probes at the outset was an effective tool to help people with social anxiety**

prepare for group activities, allowing them to address the relevant issues in advance. The prepared material also served as support for them later in the workshop.

Twelve of the 15 booklets were returned within three months of the workshop. It took a remarkably long time for the cultural probes to be returned, even though the threshold for return was purposefully kept low by including a prepaid return label.

6.4 Online workshop procedure

Due to the COVID-19 pandemic, the workshop was held online. Participatory work in a remote environment produced some limitations, but we also expected some advantages, especially for our target group. Hutchins et al. [17] found that less fear of experiencing negative evaluations and fewer negative social cognitions were ascribed to online social interaction. While these aspects were also mentioned positively by some participants in our workshop, most participants would have preferred an in-person workshop. In this respect, our experience differs from the findings of Hutchins et al. [17], which state that individuals with social anxiety often prefer online social interactions over face-to-face interactions. In our case, several participants wished for more exchanges with others and expressed that they felt a lack of group feeling, which may have been the determining factor in the preference for the face-to-face format. A contributing factor to this preference might be that all the participants have experience with self-help groups. However, the online format offered advantages in terms of accessibility and infrastructure. More participants could attend the workshop because of its low accessibility threshold; no traveling or accommodation in an unfamiliar environment were necessary for participation. We assume that this fact also contributed to our high participant numbers and low dropout rates. Regarding the results of our online co-creation format, our findings do not uphold the concerns of Sanders et al. [41] regarding the effectiveness of participatory methods in remote settings. Through our chosen methods and a shared toolkit, as proposed by Khan and Matthews [23], we obtained detailed and meaningful results for our predefined research topics, as further described in section 6.4.2. Accordingly, we conclude that **the online format is suitable for the target group because it offers a low accessibility threshold for people affected by social anxiety** and enables people from different geographical areas to participate easily. However, **an in-person workshop would be beneficial for encouraging a more substantial group sentiment and exchanges.**

In terms of technical support before the workshop, the evaluations indicated that most participants had or would not have needed the optional appointments to test the required software. For the project team, however, the appointments provided a valuable opportunity to discern technological issues in advance that would have caused the process and schedule to be delayed. With regard to this target group in particular, **we consider it worthwhile to offer optional technical support, either as a written "manual" or an optional appointment**, as some participants might be extremely unsettled by problems occurring in the group setting and stressed by the resulting time pressure.

6.4.1 Schedule and group size

The workshops were scheduled for 2.5 hours, which the participants evaluated as either appropriate or a little too long. Since workload influences the perceived level of mental stress, and excessive levels of mental stress can also impair creativity [34], it is essential to include enough time for tasks, relaxing elements, and the establishment of a good group climate. **Strict timekeeping and quick completion times should be avoided.** In addition, it must be assumed that the workshop as a social situation per se places a heavy strain on the participants [2], which indicates

that the length of the workshop should not be unduly prolonged. **From our perspective, three hours would have been reasonable for the format**, as we were behind schedule on some tasks and therefore had to excise others. Alternatively, the scope of the tasks could be reduced. **Relaxation segments (such as the “sensory journey”) should be included in the workshop** between strenuous workshop segments to reduce the strain on participants. The participant evaluations revealed that the participants had difficulty understanding or following the workshop tasks due to their anxiety symptoms that were present. Therefore, we consider it necessary to **maintain a low workload by assigning manageable tasks and communicating the tasks straightforwardly and concisely**.

Since people suffering from social anxiety often experience severe psychological difficulties in group settings [2], group size was an essential subject of the evaluation. From the workshop facilitator's point of view, both group sizes (six and nine participants) worked well, although the smaller group had more space for individual presentations and discussions due to the fixed time frame. Given that the smaller group size was also rated the best by the participants, **a group size of approximately six participants is considered appropriate**.

6.4.2 Prototyping with materials as a co-creating activity with people affected by SAD

With the prototyping activity in our participatory online workshop, we aimed at 1) engaging participants in a creative process to develop ideas through the process of making [24] and 2) using the artifacts as a means of communication between the participants and the project team [26]. The prototyping activities in the cultural probe and the online workshop were evaluated positively by the participants. Within the prototyping process, the provided materials were used remarkably diversely. Some participants used the components in the manner of "constructive assemblies" [23] in a purely additive way, combining different materials to create new structures. Others processed the materials to craft something new by cutting, gluing, or sewing. The resulting artifacts ranged from figurative to abstract, some involving more solutionist approaches—for example, artifacts for assistance in everyday situations—while others included fictional elements to communicate their needs and feelings. From our experience, we conclude that **toolkits, in the sense of “constructive assemblies,” are a valuable tool for making prototyping accessible to people affected by SAD**, as materials that can be used flexibly and additively offer low-barrier access to ideation and creative making. In addition, **emphasizing that the resulting objects do not have to meet aesthetic criteria can help participants engage in the creative process**.

In the cultural probe, prototyping was used as a facilitator to address participants' "tacit knowledge" [38] regarding their lived experiences of anxiety. We found that **lo-fi prototyping and the process of thinking through making is an appropriate approach when working with people affected by SAD, as it helps them to materialize their needs and makes tacit knowledge communicable**. The task of prototyping one's anxiety as an anxiety mascot pursues the idea of framing the issue as an external representation, thus, creating a distance between oneself and one's condition and symptoms. This procedure was evaluated as helpful in the participant evaluations and helped the participants learn something new about themselves and their anxiety and communicate their feelings and thoughts. We found that **externalizing anxiety as a physical representation assists participants to observe the topic from a helpful distance to identify their own strengths and support self-empowerment**. This finding supports Munro's approach to "appreciative co-design"[31].

The resulting artifacts impressively conveyed how the participants experience anxiety emotionally and physically. As part of the cultural probe and after prototyping the anxiety mascot, the participants were asked to describe their mascot in a profile. The anxiety mascots and their descriptions were strongly characterized by fictional elements, which provided profound insights into the underlying feelings and individual experiences of the

participants. For example, one participant described the anxiety mascot (Figure 2, left) by writing, *"The spiral is the tension that it [the anxiety] causes in my stomach"* (SP1, translated from GER to ENG). Another participant described his mascot (Figure 2, middle) as follows: *A cloud wraps me in a fog of cotton and foam so that I can hardly perceive my surroundings and my thinking becomes confused"* (SP2, translated from GER to ENG).

The valuable insights and learnings concerning individual symptoms and perceptions of anxiety that we gained from this task led us to conclude that the fictional approach was an appropriate method for facilitating communication about this very personal topic. This finding supports that of Nägele et al. [33]. They propose design fiction and thus assuming unusual perspectives on participants' realities as a valuable approach in participatory processes with vulnerable individuals.



Figure 2: Anxiety mascots: Artifacts conveying a sense of how participants experience anxiety emotionally and physically

In the online co-design session, prototyping was used as a means for participants to express and share their thoughts and visions about (imaginary) tools that could support them in coping with their anxiety. The participant evaluations indicated that the prototyping activities in our workshop design successfully contributed to this goal, thus, supporting the assertion of Vines et al. [48] that artifacts can help participants articulate and share their expertise in co-design processes. Through task definition and facilitation, we sought to establish an open-ended making mindset [3] in which participants were motivated to create ideas freely and abstractly, and unconstrained by the limitations of technical feasibility. However, a large number of the resulting artifacts tended to embed application-oriented traits. Some ideas focused on stress reduction through sensory stimuli. Others represented encouraging objects or mascots. These included objects for encouragement through recollection of the participant's own coping experiences (e.g. Figure 3, middle) and objects with inherent role model functions, reminding participants of their own goals or a desired state of mind or being (Figure 3, right). Other artifacts were rather metaphorically encoded [37] (e.g., one object in the shape of an eight on its side represented a change of perspective and the desire to see life not only from the frightened ego but from a universal perspective [Figure 3, left]) or were merely fictitious but represented specific needs (e.g., a bed as a place of refuge that could be accessed at any time and from anywhere).



Figure 3: Artifacts that express participants' ideas and needs related to coping with anxiety

Even though the crafted ideas were particularly inspiring, the focus of the evaluation was on the needs and coping strategies they represented and not the ideas themselves. All the created artifacts were suitable for this purpose, regardless of their degree of abstraction. The open-ended making approach left room for different ways of addressing the given task. Moreover, the ambiguity of the artifacts allowed for a variety of different interpretations [13] which could stimulate further dialogue [28]. However, this freedom can also be understood as a creative demand and thus may be perceived as particularly stressful by the target group. It can be particularly challenging for people affected by social anxiety to engage in a creative process that is transparent to a group of unknown people [11]. This was reflected in the participant evaluations, in which individual participants reported high levels of stress and shame in the face of the upcoming presentation.

In summary, we conclude that **open-ended making and fictional elements are suitable approaches when working with people affected by SAD, as they enable the framing of problems in an accessible form** and open the space for different ways of representing and communicating feelings, thoughts, and ideas. However, as soon as the results of these creative processes are to be shared, for example, in a discussion or presentation, it must be kept in mind that doing so can lead to considerable strain for people with SAD (see 6.4.3).

6.4.3 Presentation

At the end of the prototyping session, the participants were asked to present their idea or object to the group. Although we took into account that situations of a performance nature are experienced as severely stressful by people suffering from SAD [2], we considered these presentations of thoughts and ideas through the created objects to be a significant source of insights and learning for our process [26] [48]. Additionally, the presentation was considered a starting point for further group discussion [28]. Surprisingly, the presentation was evaluated positively by most participants.

Whether and how to comment on the individual presentations was discussed intensively within the workshop team. People with SAD often have lower self-esteem and tend to adopt a self-critical attitude [18]. They fear all types of evaluations, and positive evaluations are more likely to cause discomfort [50]. Therefore, we decided not to give feedback after the presentation and instead tried to encourage the other participants to comment on the artifacts or build on the ideas behind the artifacts. However, it proved challenging to initiate discussion among the participants. The online communication platform probably contributed to this hesitancy to a large extent, as the focus was inevitably on the individual in the event of speaking. In the second workshop, we decided to comment sensitively and appreciatively on the work that had been completed; we also asked engaging questions to provide

catalysts for discussion. Again, however, there was no actual exchange within the group. This is particularly interesting since the participant evaluations expressed a strong need for more group exchanges and feeling.

Our experience with our workshop design suggests a need to rethink how participants present their artifacts and adapt the process to better meet the needs of people with SAD with regard to creating a sense of group feeling. Concluding our findings, we argue that **presenting the created artifacts in front of all the other participants should be avoided, as the resulting stress can negatively impact the creative process.** Instead, an informal conversation between participants could be initiated in small groups to avoid one person being the center of attention. The latter represents a challenge to be overcome, especially in online workshops.

6.4.4 Post-workshop (self-)observation

In the final part of the participatory format, the participants were asked to embed and use their (fictional) objects in an everyday context—as if they were actual tools or companions—and observe and document their experiences with them. To some extent, the insights we gained from this task were redundant with respect to what we learned in the other parts of the workshop. From the participant evaluations, we concluded that the task put pressure on some participants and that it was difficult for others to understand. One possible reason for the task being difficult to understand and execute was that the artifacts that emerged from the prototyping sessions were particularly diverse and, in some cases, metaphorical, fictional, and open-ended. This may have complicated their performances as possible everyday assistants. Nevertheless, case studies concerned with developing practical solutions could benefit from this activity. In our case, we would argue that the benefits offered by the self-observation after the workshop were disproportionate to the burden involved.

6.4.5 Workshop evaluations

We recommend **offering participants an anonymous evaluation survey after the conclusion of the participatory format** in order to allow the procedure to be evaluated by the target group. Anonymity may help participants express their honest opinions, especially when working with people affected by SAD.

7 CONCLUSION AND OUTLOOK

As social anxiety is one of the most common psychological disorders, whose impact may increase due to the COVID-19 pandemic, it is essential to investigate and develop novel ways to support people affected by SAD. While participatory design is an established methodology for including target groups as experts in the design process, developing and conducting participatory formats with individuals affected by social anxiety is particularly challenging due to the psychological characteristics associated with this mental disorder. In this paper, we discussed a methodological approach to participatory design with people affected by severe social anxiety. Based on what we learned from the implementation, we provided recommendations for implementing participatory (online) formats specifically tailored to the needs of people with SAD. Adopting material practices, such as "making," to support self-reflection in an embodied form and to use physical artifacts as tools for communication was vital to our approach. Fostered by the COVID-19 pandemic, it is likely that remote settings will gain importance for participatory approaches. In this paper, we have outlined the potential of prototyping as a material practice for promoting co-creation in remote settings. We believe that further research should be conducted to investigate and develop prototyping approaches and practices for online formats, including ways in which the use of physical materials and fictional and lo-fi making can support ideation, discussion, and collaboration in such settings. Our

work contributes to the research on participatory formats, especially those concerning online settings and psychologically vulnerable groups.

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