

Co-designing a Bespoke Wearable Display for People with Dissociative Identity Disorder

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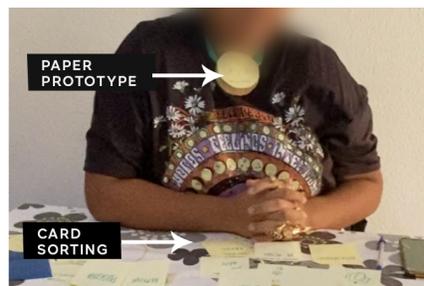


Figure 1: Stages of the co-design process of creating a bespoke technology with a person living with DID. Left: unfinished storyboard that the co-designer had to fill-in (last three slots). Middle: paper prototype used during the experience prototyping activity and MoSCoW matrix resulting from the card sorting activity. Right: final concept, a pendant and necklace that displays a representation of the fronting personality and pronouns.

ABSTRACT

Dissociative Identity Disorder (DID) is characterized by the presence of at least two distinct identities in the same individual. This paper describes a co-design process with a person living with DID. We first aimed to uncover the main challenges experienced by the co-designer as well as design opportunities for novel technologies. We then engaged in a prototyping stage to design a wearable

display (WhoDID) to facilitate in-person social interactions. The prototype aims to be used as a necklace and enable the user to make their fronting personality visible to others. Thus, facilitating social encounters or sudden changes of identity. We reflect on the design features of WhoDID in the broader context of supporting people with DID. Moreover, we provide insights on co-designing with someone with multiple (sometimes conflicting) personalities regarding requirement elicitation, decision-making, prototyping, and ethics. To our knowledge, we report the first design process with a DID user within the ASSETS and CHI communities. We aim to encourage other assistive technology researchers to design with DID users.

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ASSETS '22, October 23–26, 2022, Athens, Greece
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ACM ISBN 978-1-4503-9258-7/22/10.
<https://doi.org/10.1145/3517428.3550369>

CCS CONCEPTS

• **Human-centered computing** → **Accessibility.**

KEYWORDS

Dissociative Identity Disorder, Co-design, Wearable, Social Encounters

ACM Reference Format:

Patricia Piedade, Nikoletta Matur, Catarina Rodrigues, Francisco Cecilio, Afonso Marques, Rings of Saturn, Isabel Neto, and Hugo Nicolau. 2022. Co-designing a Bespoke Wearable Display for People with Dissociative Identity Disorder. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '22), October 23–26, 2022, Athens, Greece*. ACM, New York, NY, USA, 4 pages. <https://doi.org/10.1145/3517428.3550369>

1 INTRODUCTION

Dissociative Identity Disorder (DID), formerly known as multiple personality disorder, is a clinical condition involving a “disruption of identity characterized by two or more distinct personality states” [1]. It consists of a sudden and temporary discontinuity in the sense of agency and self [1]. DID is a complex and controversial diagnosis [2, 6], often associated with childhood trauma and abuse [4], that allows the host, who may be unable to deal with overwhelming stress, to pass control of their body (i.e., switch) to an alternative identity, the alter. The term ‘alter’ is often used to describe other identities within the body. Alters can differ “in affect, behavior, cognition, consciousness, memory, perception, and sensory-motor functioning” [1].

People living with DID experience daily challenges such as stigma, fear, and maintaining relationships [9]. Although previous work has proposed adopting a lens from disability studies and incorporating the expertise of assistive technology researchers to support people with psychosocial disabilities [7], to the best of our knowledge, there is no previous research exploring the role of technology in supporting people living with DID.

In this paper, we describe the process of designing a bespoke technology to enhance social interactions by engaging in a co-creation process with a person living with DID. We contribute with 1) a report on the design process, which offers preliminary practical and ethical considerations to design with people living with DID; and 2) the design of a wearable display (WhoDID) to be used by the sixth author of this paper.

2 THE DESIGN OF WHODID

This section describes two 2-hour in-person co-design sessions with a person living with DID. We took inspiration from the Double Diamond design process by first aiming to understand and define the challenge and then develop and test different solutions. The co-designer is a five-personality DID system (i.e., group of host and alters). The host, Onyx, is 20-year-old and has been diagnosed with DID for a year. They share their body with Ana, a 20-year-old protector (alter who handles stressful situations), Oliver, a 17-year-old caretaker (alter responsible for assuring the physical and mental needs of the body), Thalia, a 26-year-old caretaker, and Charlotte, a 7-year-old alter. This system lives in relative harmony, communicating and making decisions collectively.

2.1 Exploring the Problem Space

We began our co-design process by investigating the daily struggles of living with DID. We conducted a **semi-structured** interview

in a relaxed environment to create a safe space for learning and getting to know our co-designer. For added comfort, only two team members were present: an interviewer and a notetaker.

We inquired about demographics, DID, and technology. We started by explaining the project’s goal and then used **directed storytelling** [3] to harness detailed descriptions of our co-designer’s experiences. We then asked follow-up open-ended questions.

This session enlightened us on many of the challenges faced by our co-designer. Social encounters were one of the main emergent discussion topics. The co-designer expressed awkwardness and embarrassment in communicating which alter is fronting (i.e., in charge of the body). Moreover, having people misidentify alters was a source of frustration and misunderstandings. We thereby focused on facilitating in-person communication through externalizing who in the system is fronting. Our co-designer showed great interest in using a wearable device to indicate the fronting alter.

2.2 Exploring the Solution Space

Having a clear problem statement, we conducted a co-design workshop to craft the details of the wearable. We documented this session through video recordings, photos and notetaking.

We crafted two unfinished **storyboards** representing challenging in-person communication scenarios referenced by our co-designer (Figure 1). The first storyboard illustrated the co-designer hanging-out with a friend and being disrupted by a switch. The second storyboard portrayed meeting a friend on the street when the host was not fronting. We discussed how we might facilitate these situations using technology and asked the co-designer to finish filling both storyboards accordingly.

We also conducted a **card-sorting** activity using the **MoSCoW prioritization** [8] technique to understand the co-designer’s views on collectively brainstormed features catering to their needs, determining which should be included (or excluded) in the prototype. The cards represented the features and the co-designer categorized them into one of the four MoSCoW priority groups: Must have, Should have, Could have, and Will not have. The resulting MoSCoW matrix informed the prototyping of a wearable necklace display and its companion mobile app - WhoDID.

To simulate the use of WhoDID, we crafted a **low-fidelity prototype** of our wearable using cardboard and post-its (Figure 1). We recruited a recent friend of the host, unacquainted with the whole system, to conduct an **experience prototyping** activity [5]. We simulated a social interaction between the co-designer and their friend, during which a switch occurred. When the co-designer touched the “screen”, a Wizard would switch the post-it to display the now fronting alter. During this session, an actual switch occurred. This helped solidify the robustness of the WhoDID concept, as we avoided mentioning the switch, yet the friend was aware with whom they were interacting.

Finally, to complement the wearable, we prototyped a **high-fidelity companion app** using Figma, which enabled the set up of alters’ profiles and control of the appearance of the wearable display. We demoed the app and discussed its features with the co-designer.

3 FINDINGS AND DISCUSSION

In this section, we highlight the main findings regarding the design of WhoDID and lessons learned about designing with someone living with DID.

3.1 WhoDID Design

Supporting In-person Social Interactions. One of the co-designer’s main challenges was their difficulty conveying the fronting alter after a switch without awkwardness and unpleasant feelings. While conveying a switch through digital technologies is relatively straightforward using existing features of communication platforms (e.g., social media profiles, PluralKit Discord bot), there is not a similar tool for in-person communication. Thus, the co-designer explicitly focused on this challenge and finding new ways of enhancing in-person communication by easing the externalization of the alter in charge.

Designing a Wearable Display. We explored several alternatives of wearable form factors (e.g., bracelet, watch, rings) for displaying the fronting alter. The co-designer strongly preferred a pendant in a necklace due to its flexibility to be highly visible or hidden at will. During the experience prototyping activity, we observed that it was natural for the co-designer to perform swipe gestures on the display due to its familiarity and robustness to accidental taps.

Privacy Concerns. The main safety concern emerging during the design process was related to using biometric sensing to detect a switch automatically. While this feature could reduce the interaction with the device and seemly transition between alters, the co-designer reached a consensus that each alter should have the freedom to choose when to identify themselves. This identification process should not attract attention from onlookers; flashing lights or sound cues should not be used.

Companion App Features. Being able to customize the visual representation of each alter is a key feature. WhoDID supports the personalization of background color and image. Interestingly, the co-designer preferred to display the alter’s pronouns over their names as a balance to provide enough information for a respectful social interaction without disrupting the norms of meeting someone for the first time (i.e., asking for their name). A central concern was the possibility of a given alter making destructive changes to another alter’s profile (e.g., deleting it). As a risk mitigation measure, WhoDID supports an edit window of 15 days, which allows the user to undo any action. Although this feature does not prevent destructive behaviors, it is a coping mechanism. We believe these challenges are fertile ground for usable privacy/security research. Lastly, to tackle the awkwardness when a friend of the system first encounters an unknown alter by chance, WhoDID features proximity notifications, allowing the system to choose from trusted individuals who should be informed of who is fronting when facing a possible chance encounter.

3.2 Lessons Learned from the Design Process

Wait for Consensus As the system contains multiple alters within the body, our co-designer expressed that it is vital to allow them enough time to reach a consensus when decision-making, as different alters may have different opinions. Thus, design processes

must account for time (possibly even over several days) and allow for “internal” discussions.

Consider Diversity Throughout the design process, our co-designer stressed the diversity of DID systems, from the number of alters to the ease of communication among alters. Though we focused on a solution tailored to our co-designer, the final design is highly customizable in terms of the number of alters, displays. For instance, from our co-design process until the time of writing this paper, a new alter appeared within the co-designer system. When discussing initial research with our co-designer, even in simple aspects such as DID-specific terminology, we found that our co-designer had their unique perspective and preferences. The diversity in the experiences of people with DID and in the information relating to this diagnosis calls for added double-checking of all researched information with the specific co-designer.

Ponder Ethics Triggering switches are one of the main ethical concerns when designing with individuals with DID. Switches produce both physical and mental changes, possibly even pain. Thus, there are critical implications for designers trained in participatory practices of including stakeholders in the design process. Participatory activities that require decision-making, discussion, and consensus (e.g., prioritizing features) can be highly problematic as they can trigger several switches. Moreover, testing prototypes with the various alters may require a longer time frame and the use of asynchronous/remote methods to leverage naturally occurring switches rather than trigger them.

4 CONCLUSION AND FUTURE WORK

We have presented the co-design of a bespoke wearable display to support in-person social interactions for people with DID. We highlight findings related to the design of WhoDID and the design process itself. Results show that to co-design with people with DID, it is not feasible to make decisions based on opinions from one alter; we should aim for consensus of the different alters and double-check whether all voices are heard. We also reflect on the ethical concerns of this activity as switches impact the individual comfort and well-being. Future work will develop a functional prototype and evaluate its effectiveness in supporting our co-designer’s needs in the wild.

ACKNOWLEDGMENTS

This work was supported through FCT’s projects UIDB/50009/2020 and SFRH/BD/06452/2021.

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