# Empathic Design for and with Vulnerable Women in Secure Hospital Services

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# Abstract

We present our work in progress on the design process of a set of interactive objects, the Spheres of Wellbeing, for and with women in secure hospital services. The women present a very vulnerable and difficult-to-treat group due to profound emotion regulation problems that impact on their behavior, sense of self and relationships with other people. Interactions with the *Spheres* are designed to motivate engagement with important therapeutic exercises of their specialist treatment Dialectical Behavioral Therapy (DBT), and to improve their quality of life and mental wellbeing more generally. This paper first briefly outlines the basic concept of the Spheres of Wellbeing, as they have been informed through a close, personfocused collaboration with hospital staff. We then describe in more detail our empathic approach to actively engage the women in creative activities that allow for a personalized design of the Spheres by each woman.

# **Author Keywords**

Mental Health; Vulnerable Individuals; Secure Services; Ethics.

# **ACM Classification Keywords**

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## Introduction

This research is targeted at a group of six women who have a dual diagnosis of a mild to moderate Learning Disability (LD) and Borderline Personality Disorder (BPD). The women present a very vulnerable group due the severity of their mental health problems, often a history of abuse, and their specific circumstances of requiring secured treatment, which means that they lose their liberty.

LD is a lifelong disability that usually causes difficulties in learning, understanding and problem solving, limits a person's attention span and impacts on interactions and communications with others. As a result, individuals frequently experience situations that they find frustrating or provocative, and they have greater difficulty in developing a sense of independence [1].

BPD is characterized by difficulties to regulate emotions, to control impulsive and disruptive behaviors (e.g., self-harm) as well as disruptions in a person's self-image, and the ability to form and maintain relationships with other people [6]. In addition, BPD often co-occurs with other major disorders (e.g. Depression, PTSD [4][7]) and is associated with extremely high rates of suicide. The underlying deficit in emotion regulation is assumed to originate in a person's emotional vulnerability and her growing up in an environment characterized by a pervasive pattern of invalidation, neglect and abuse [6]. For example, it is estimated that about 75% of women suffering from BPD have a history of sexual abuse in childhood.



**Figure 1**. Example of the Mindfulness Sphere.

Due to the emotion dysregulation, individuals with BPD present a great treatment challenge, since their behavior is often unpredictable, impulsive and resistant

to therapy. At the same time, the women are in need of attention, care and time to be spent positively with other people, and effective treatment approaches.

For the treatment of BPD, Dialectical Behavioral Therapy (DBT) has been shown to be effective, teaching individual's important skills such as distress tolerance or mindfulness. The therapy also focuses on validating the individual by empathically acknowledging her feelings, thoughts and behaviors, and attempts to continuously motivate and reinforce her to practice the taught skills. The underlying purpose of the program is to enhance an individuals' quality of life [6]. The design concept of the *Spheres of Wellbeing* builds on this therapy approach, while interactions with the Spheres are aimed at supporting the women in practices of mindfulness, to help them tolerate emotional distress and to strengthen their sense of self.

# The Spheres of Wellbeing

The basic design concept of the *Spheres of Wellbeing* is informed by the literature and has been established in close collaboration with staff at the hospital – including members of the R&D department, staff nurses and a therapists working with the women – to ensure that the objects are safe for the women to use and present a suitable addition to their treatment and care plan (for more details see [8]).

The Spheres of Wellbeing are a set of three objects: The *Mindfulness Sphere* is a ball-shaped artefact that assesses and reflects a person's heart rate through soft pulsating vibrations and colourful lights, providing a new, experiential way of bringing awareness to one's body. The *Calming Sphere* is a bead bracelet that the women can hold on to at times of emotional distress,







**Figure 2**. Example of the Calming Sphere bracelet.



**Figure 3**. Example of the Identity Sphere.

and the *Identity Sphere* gently invites the women to engage with short personalised videos, allowing them to explore and reconnect to meaningful experiences and positive aspects of their self (see Figures 1-3).

A focus on aesthetic appeal and physicality – enlivened by the technology – may lead the women to perceive these objects differently to materials commonly used in formal therapy, which can reduce stigma and lower motivational barriers to engagement. As such the *Spheres* can provide a novel means to promote the learning and practice of therapeutic skills. Their basic design creates the starting point in a co-creative process that allows the women to personalize them.

# **Co-Creative Design Process with the Women**

To increase the potential for engagement with the Spheres, each woman will be invited to contribute to a personalized design of her Spheres objects through a series of 4-5 creative sessions with one of the researchers, in which they will craft visually attractive pieces from a variety of art materials. For example, the women are encouraged to make their own clay beads for the Calming Sphere, to grow beautiful crystals to be encased as decorative elements in their Mindfulness Sphere or to capture imagery for their Identity Sphere.

Each of the 2 hour sessions are conducted within the women's familiar environment to reduce any anxiety that they may experience during these activities. Responding to ethical demands, the sessions are also accompanied at all times by a regular member of staff, safeguarding both the women and the researcher. These creative engagements are further intended to promote a calmer and less threatening atmosphere when working with the researcher and are designed to be both stimulating and enjoyable. As such, they may also help raise the women's self-esteem as they learn achievable skills or discover unknown strengths [5].

With a positive focus on accepting and continuously validating the women, the creative sessions are anticipated to enable the researcher to gain a more empathic understanding of the women. To enable the formation of a positive and empowering relationship between the researcher and the women [8], the researcher will take on a nurturing style in assisting the women in their engagements with different craft materials, recognizing their personal preferences and responding flexibly and non-judgmentally to their interests, capabilities and needs; similar perhaps to the role of a therapist trying to enable an assistive relationship with an individual [6].

To this end, the activities between the researcher and the women enable gentle explorations of different materials and designs that respond to aspects of femininity and beauty. In designing pieces together in small achievable steps (i.e. kindly guiding the women in the process of making their own clay beads; see Figure 4), the researcher can tentatively explore aesthetics with the women (color preferences, how they attend to the creative activity). Many of our engagements with the women relate to explorations of their body, informed by existing practices on the unit where staff look after the women (e.g., assisting them to do their nails, or brushing their hair).

Such like activities invite a reciprocal process whereby the researcher progressively gets to know facets of the women, i.e. their likes and dislikes, whilst it is anticipated that the women will experience validation



**Figure 4**. Step-by-step making of beads from polymer clay using the Kaleidoscope technique whereby one shape is repeated to create beautiful symmetrical patterns. and support in return. Albeit hugely challenging in the context of the women's emotional or interpersonal difficulties, this process may enable the relationship to flow and help negotiate trust.

# Discussion

The co-creative activities with the women enable them to actively contribute to a personalized design of their artifacts, invite creativity, potentially raise their selfesteem [5], and may promote an empathic relationship between them and the researcher [9]. This approach however also raises a variety of concerns:

Firstly, the women's low emotional pain tolerance, hopelessness or rapid onset of extreme shame [6] may at times affect the research activities. This will require the researcher to respond to these dynamics and the women's needs sensitively and flexibly, which can challenge the adherence to a pre-set research agenda.

Secondly, described interpersonal and emotional difficulties of the women may pose emotional burdens on the researcher, who takes on the role of an assistant that continuously supports and empowers the women in their process of making things and exploring themselves. Whilst staff support these sessions and safeguard all involved, little consideration is often given to how researchers will cope in these contexts, cf. [2].

Thirdly, the fostering of a close relationship with the women can lead to biases in their engagement with, and perceptions of the *Spheres*. To minimize conflicts with scientific standards for objectivity, the researcher needs to create space to step back from the activities and to critically reflect on their own practices [3]. We hope that our person-focused and empathic design

approach and related concerns will spark interesting discussions at the workshop.

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# References

[1] Chilvers, J., Thomas, C., and Stanbury, A. The impact of a ward-based mindfulness programme on recorded aggression in a medium secure facility for women with learning disabilities. In *Journal of Learning Disability and Offending Behavior 2*, 1 (2011), 27-41.

[2] Dickson-Swift, V., James, E.L., Kippen, S., and Liamputtong, P. Doing sensitive research: what challenges do qualitative researchers face? In *Qualitative Research 7*, 3 (2007), 327-353.

[3] Johnson, R. Rogers, Y., van der Linden, J., and Bianchi-Berthouze, N. Being in the thick of in-the-wild studies: The challenges and insights of researcher participation. In *Proc. CHI 2012*, 1125-1144.

[4] Lieb, K., et al. Borderline personality disorder. In *Lancet 364* (2004), 53-461.

[5] Liebmann, M. *Art therapy and anger*. Jessica Kingsley, 2008.

[6] Linehan, M.M. *Skills Training Manual for Treating Borderline Personality Disorder*. Guilford, 1993.

[7] Swenson, C.R. How can we account for DBT's widespread popularity? In *Clinical Psychology: Science and Practice* 7 (2000), 87-91.

[8] Thieme, A., et al. Design to promote mindfulness practice and sense of self for vulnerable women in secure hospital services. In *Proc. CHI 2013*.

[9] Wright, P., and McCarthy, J. Empathy and experience in HCI. In *Proc. CHI 2008*, 637-646.