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CO-VISUALISE THE IMPACT OF SICKLE CELL

How can we use design thinking to investigate and visualise the impact of Sickle Cell?

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INTRODUCTION

Sickle cell is a complex, multifaceted condition that presents significant challenges for individuals, communities and public health organisations. The inherited disorder affects the structure and function of the red blood cell, causing them to form a sickle shape. Sickle Cell (SC) affects approximately 20 million people worldwide[1], and is one of humans' most common inherited blood disorders. Patients with this condition face a range of physical, emotional, and social challenges due to the unpredictable nature of the disease. It is particularly prevalent in regions such as Africa, the Caribbean, Mediterranean, Middle East and India. In England, around 17,000 individuals are estimated to have the condition, and 8% of black people carry the gene[2]. Despite the relatively small number of affected individuals in the UK, SC poses significant public health implications. This study endeavors to fill a research gap by focusing on human-centered design[3], in the context of this condition, an area where limited prior research exists. The study leverages the principles of design thinking[4] and system thinking to investigate and visualise the impact of SC. The fundamental principle explored in this study is designing for empathy. 'Design for Sickle Cell[5]' (D4SC) initiative was developed to bridge the gap between art, design and science within the Sickle Cell landscape to promote collaboration and knowledge exchange.

AIMS AND OBJECTIVES

This study aims to investigate and visualise the condition's impact from a multi-stakeholder perspective. The goal of this broad study approach is to capture a wider understanding of the impact of the condition.

The use of human-centered design to promote empathy.

- To develop and design tools to communicate the impact of the condition.
- To develop prototypes that can inform an innovative mobile SC exhibition.

METHODS AND MATERIALS

Techniques from social constructionism, phenomenological qualitative research[6] and user-experience research were utilised to create a novel methodology for this small-scale study. The methodology involved a multi-step process combining the double diamond, system thinking, and the action research frameworks to gather insights that guided the development of this design research project. Project duration: October 2022- April 2023.

Research questions

A- How can we use design thinking to investigate the impact of Sickle Cell?

B- How might we visualise the impact of Sickle Cell?

Research process

- Seven semi-structured interviews with SC experts- 3 patients, 1 parent, 1 healthcare practitioner, 2 support staff. Maps were shown to participants as prompt. Participants were asked to draw/ visualise the impact of the condition.
- An interactive exhibition- An exploration of patient and public engagement, collaboration with social engagement project 'Invisible Warrior'. Approx. 60 individuals took part.
- Two focus group- 2 SC experts, 1 healthcare practitioner, 2 designers. The discussion focused on prototypes and the final concept; mobile SC exhibition.

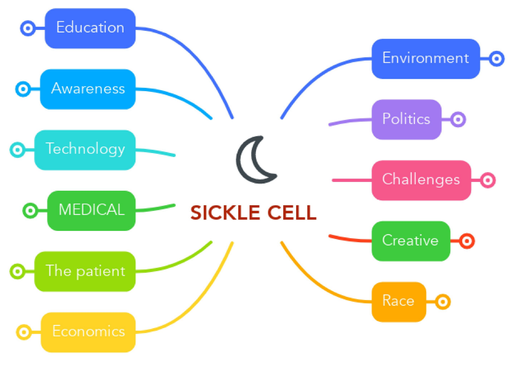

Figure 1. Map prompt used during the interviews

Figure 2. Exhibition concept prompt for focus group

RESULTS

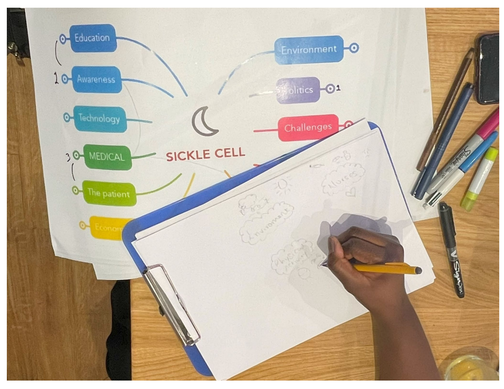

Figure 1. Semi-structured interview: participants visualised their experience/ understanding of the condition, images show two in-person interviews. (January 2023- April 2023)

Quotes from interviews:

- "When I had jaundice in my eyes, I got teased for it quite a bit…lack of awareness led to that…"
- "…the horrible level of health inequalities…"
- "I spent 4 hours sitting in the waiting area because they didn't believe I was in pain, and that's life or death for a sickle cell patient."

Figure 3. Interactive Exhibition- Creative expression

Drawings created by patients and the public, conveying their understanding of SC. Many focused on showcasing the cell, while others used their drawing to communicate their lived experience. This activity will need to be repeated to differentiate patient and public results. This is a promising exercise to develop visual communication tools for the condition.

Themes from primary and secondary research:
1- Lack of awareness and education on SC. 2- Healthcare disparities and inequitable access. 3- Lack of holistic patient-centred care and empathy. 4- Challenges in communicating complex medical concepts about SC.

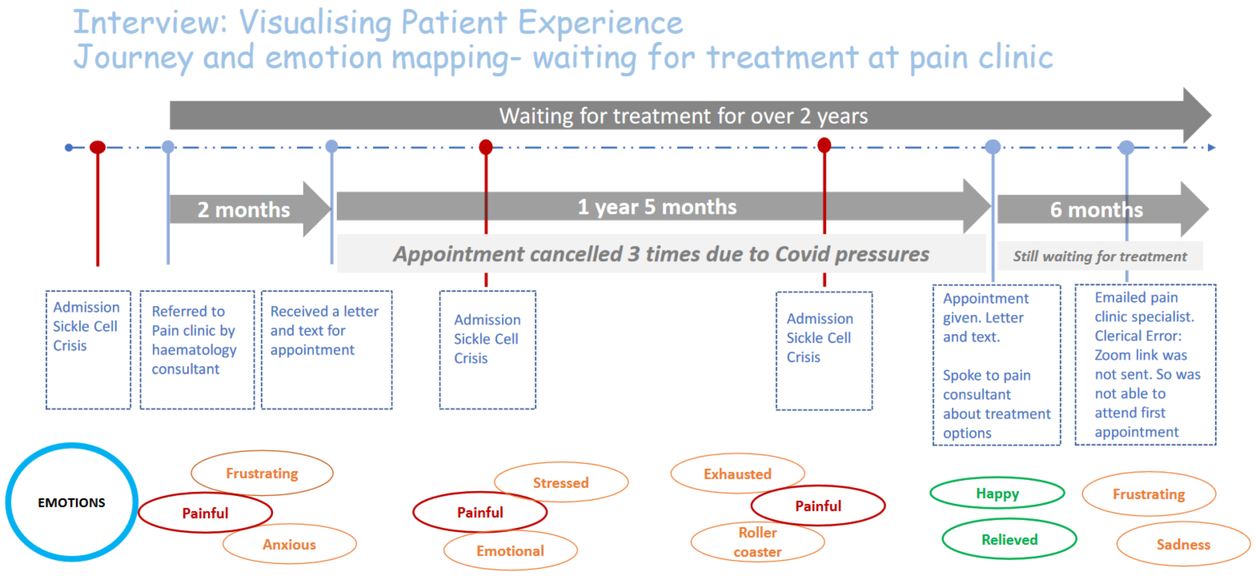

Figure 2. Journey and emotion map[7] of a Sickle Cell patient's experience waiting for treatment. Insights for this map was gathered from a story shared during a semi-structured interview.

DISCUSSION

The project highlights the importance of design thinking, system thinking and collaboration in developing innovative healthcare solutions for this complex health condition. The study demonstrates the value of a multi-stakeholder approach to designing for empathy. It shows the potential of visualising the impact of Sickle Cell to promote understanding and awareness of the condition. Participants engaged in creating visual communication tools to convey this complex multifaceted condition. Art and design became strong mediums to express and communicate this health condition.

Key Takeaways:

- There is a strong need for awareness and education on Sickle Cell.
- Design research in healthcare can foster innovative solutions, but its effectiveness hinges on a multidisciplinary approach.

Future Work:

To facilitate the further advancement of the insights and concepts developed in this study, collaborations, funding, and additional research endeavors will be necessary. This small-scale design research study within the field of Sickle Cell holds significant promise for understanding the impact of this complex condition.

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