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709. The paradox of personalising wearable health design: from ostomy to fashion accessory?

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ABSTRACT *This research paper explores the challenges of combining personalized design approaches with industrial production of wearable health devices, which are associated with taboo, stigma and a need for discreteness. Current research states that becoming a user of a wearable medical device significantly compromises the sense of identity (Kelly 2014). Jacobsen (2014) demonstrates that assistive products are considered material for defining, constructing, shaping and expressing the self. Responding to this, several scholars call for a need to address individual wearable health design (Royeen 2015; Bush 2015; Pullin 2009). Based on a case study of the Danish medico-company Coloplast's development of SenSura Mio, a design-awarded ostomy bag created for individual fit, the paper presents how the designer involved was highly inspired by fashion and textile design to work with ostomy wearers' sense of self. Involving feedback from wearers of SenSura Mio ostomy bags, the case conveys how personalized design could contribute to individual qualities by exploring how functional and expressive drivers can heighten the experience of wearing an ostomy bag. The paper finally discusses if an ostomy bag can be considered as a fashion accessory?*

Keywords: sense of self, personalized design approach, wearable health design, taboo, fashion accessory

Introduction

Taboo is defined as something that is avoided or prohibited for social reasonsⁱ. Such reasons vary, but when it comes to ostomy careⁱⁱ, they often relate to ignorance of disease and functions or situations concerning body waste, which are shrouded in stigma because of their intimate and personal nature. Functionality and discreteness are therefore key design parameters for ostomy wearers. Product design for this particular target group serves as an interesting case study because what is involved is actually the wearers' sense of self (Bendix 2016).

This paper presents different wearer perspectives and current product development, in particular Coloplast's design award winning ostomy bag. The SenSura Mio is highly inspired by textile and fashion design to create a wearable health device that fits individual needs. It is an attempt to frame the challenge of using personalized design approaches to industrially manufacture wearable health devices. To critically reflect and raise new questions, a three-hour workshop facilitated new perspectives of a former stoma nurse, the former designer of SenSura Mio and a person who wears it. Finally, the paper encounters these insights in a concluding discussion.

Designing health wearables in the area of taboo, stigma and discreteness

'Wearable wellbeing' is a term coined by Bush (2015) concerning designed health objects that are habitually worn by persons and extend beyond a focus on the medical body. This notion might have been the starting point as well as the final goal for Coloplast's re-design of SenSura Mio (Figure 1).



Figure 1: The design development of Coloplast's ostomy bags since 1957

What is particularly notable in the design is the change of material and colour. Since the foundation of the company, it has refined its products also to include underwear for ostomy wearers. This led to a radical shift in the focus of the company (Meyer 2016). Working with textile designer Astrid Krogh and fashion designer Anette Meyer in developing underwear with a high

stretch-ability, the partnership included a personal design approach for the product to look like ordinary underwear.

In 2009, Coloplast hired industrial designer Jakob Bendix to help develop a completely different product line in the ostomy area. Interviewing him, while he was still employed at Coloplast, his viewpoint on what he was creating was *appealing* products (2016). Interviewing him in 2018, he has now left the company and is therefore interesting due to his experience, to bring into play the questioning of whether an ostomy bag can be a fashion accessory.

The design process of SenSura Mio

The first thing Bendix told in 2016 was that Coloplast included non-users to clarify existing product associations, only to find that both colour and material needed to change dramatically as the existing devices had 'Prosthetic aesthetics'.

To develop a premium feel, Coloplast started to experiment with other materials instead of the traditional non-woven fabric, which is an industrial, medical and foremost cheap see-through material. One could argue that this effect does not radiate discreteness for the wearer.

Bendix also started to do design explorations with new colours (2016). Using physical prototyping methods instead of 3D renderings on a computer gave him insight into the material qualities and how different colours appear underneath various clothing e.g. under a white shirt (Figure 2).



Figure 2: Bendix tests different grey colours underneath white cotton to see which tone of grey is less likely to reflect shadow back onto the skin of the wearer

Focussing on the wearers' sense of self led to the opportunity of aesthetic choices in the design process, especially to emphasize lifestyle perspectives of having a stoma. Furthermore, Coloplast starts to portray the persons with an ostomy differently in their marketing material. In Figure 3, a man stands in his bathroom with, among others, a bathtub with a Vola fixture designed by Arne Jacobsen.



Figure 3: Image from Coloplast's marketing material

The wearer is getting ready for what is probably another day in the office. His ostomy bag blends in with the colours of the interior and is purposely, according to Bendix, designed in grey to be discrete (2016). He explained that the colour he chose in the end was the result of an interminable experiment with pens and black ink. With dye dip techniques, also used in textiles design, Bendix tested several nuanced grey samples of textiles upon white cotton before he was finally able to produce the most suitable grey nuance of SenSura Mio, a technical detail Coloplast has now patented.

Can an ostomy bag be a fashion accessory?

Coloplast's design approaches and the creation of the object SenSura Mio trigger thoughts of accessory design methods and practices. Jack Cunningham (2005), who is a researcher and maker of contemporary jewellery, is of interest here as he enrolls a set of relationships between the maker, the wearer, and the viewer when designing accessories for the body. Similar to Bendix's relation to the wearers' sense of self, the ostomy bag can be seen as an accessory for the wearer as they are both intimate objects carried closely to the body. It is therefore interesting to explore what the similarities are between accessory design and SenSura Mio. So, I presented these questions to wearers of SenSura Mio to reflect how Bendix's design, inspired by fashion and textiles design and similar to accessory design, contributes to individual design qualities for the wearer.

Questionnaire

An online questionnaire was posted in a Danish ostomy community in a closed Facebook group. The aim was to explore if both functional and expressive drivers can heighten the experience of wearing the SenSura Mio. In previous findings, Møller and Bang (2016) identified the nature of the accessory as:

- A carrier of the wearer's identity

- Embedded with personal and emotional stories
- A symbol of significance to the wearer
- A conveyer of stories about the wearer and reminder of whom the wearer is
- An integrated part of the wearer
- Having bodily qualities
- Having emotional, memorable and material value to the wearer.

18 participants ranged from the age of 23 up to 69 - 16 women and two men, filled in the questionnaire.

Analysis

When asked about three things the wearer thinks of as inherent qualities of SenSura Mio, several different associations appeared. Words as 'ethical pretty', 'unique', 'applicable', 'discrete', 'soft', 'nice look', 'nice to touch', 'neutral' and 'light',

One person states that apart from the colour, SenSura Mio looks like other ostomy bags. Another feels insecure about the 'lightness' because of the 'thin' product, whereas one highlights this as a good quality. The insights gathered from the questionnaire show that all 18 participants are very individual.

When asked if they think that SenSura Mio is designed to match their identity, 44.4 % disagreed (Figure 4).



Figure 4: Screenshot from the Google questionnaire on the question if the wearers think SenSura Mio is designed to match their identity

The negative answers written after the opportunity to mark no highlights that almost 50 % of the participants think that SenSura Mio is a design that has to fit all. One writes:

'My ostomy bag has nothing to do with my identity. It is a practical measure that just simply has to work!'

Two of the participants write that the question is odd, and one follows up with this reply:

'I suppose it is designed to be as discrete as possible and fit the surroundings of the ostomy to avoid leaks and skin issues. That has nothing to do with identity.'

The next question raises a similar concern, and here 61 % of the wearers think that SenSura Mio is designed to fit their personal preferences. Some of the notable replies are:

'It works, and I trust it, so I do not have to think about it except when I have to change it.'

Another replies that SenSura Mio is a little more elegant than other ones the participant has tried.

In return, a response was that the participant is confident that SenSura Mio is designed to fit all which is an interesting dilemma, due to insights of Bendix's inspiration and exploration towards choices in regards of the material, colour, overall finish and aesthetics.

Takeaways

Analysing the participants' replies to the question of whether the design of SenSura Mio is of importance to them, I start to feel uncomfortable as I go through the questionnaire answers. My sense of discomfort is both due to personal embarrassment but also an unfulfilled interest into what is going on when you are an ostomy wearer. How can you even propose to compare the qualities of accessory design with the qualities of a person's ostomy bag? This makes me start to explore persons with stomas that deal with their condition out in the open, putting aside taboos, stigma and discreteness.

Public Ostomy Wearers

Getting access to the closed forum COPA on Facebook I see that several ostomy wearers show images of their ostomy bags, daily challenges and obstacles. There seems to be a tendency, especially on social media, for ostomy wearers to share their 'everyday life' openly. Danish Astrid is one of them (Figure 5).

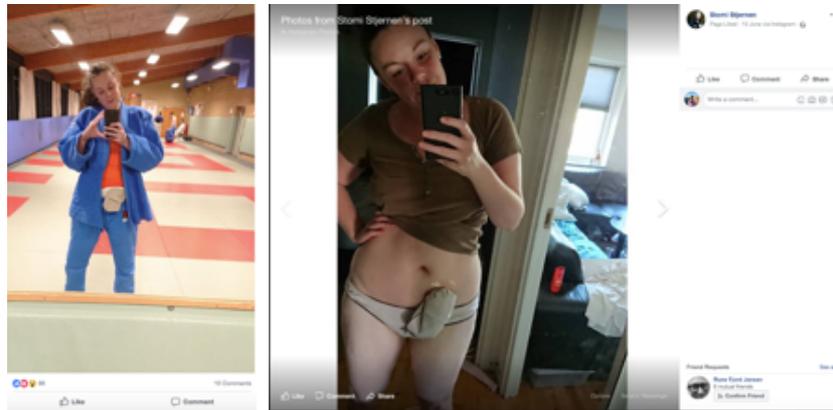


Figure 5: Astrid and her public life on social media

Since her operation in 2017, she blogsⁱⁱⁱ openly about her everyday challenges and issues, and on Facebook and Instagram^{iv}.

Role models



Figure 6: Heather Matson is a public figure and ‘small cottage’ manufacturer and retailer of personalized ostomy covers

Maybe Astrid is a role model for other stoma patients in the way that she presents herself and shows that you do not have to hold back even though you have an ostomy. Other persons with an ostomy, who have gone public, also share their ideas when it comes to personalising the design of your ostomy. One of the designers that creates and sells different ostomy covers is Heather Matson from the US who, with no creative background, taught herself to sew (Figure 6). Under the title ‘I design my own ostomy bag to feel sexy’ she is represented on many video channels, explaining her story^v.

Both Astrid and Heather share honest and reflective thoughts about how they deal with their conditions.

When recently interviewing Bendix (2018) to understand the difference in large industry versus smaller cottage industries in order to identify challenges in personalising wearable health design, he explained that Coloplast has a fifteen-meter long production machine (costing 1 million Danish Kroner per meter) to produce approximately 167 different styles of SenSura Mio. So adding this up with various sizes and colours would be a difficult and heavy multiplication of the production unit.

Workshop

To create a dialogue and critically reflect if an ostomy bag should be a fashion accessory a workshop was held. Four participated; Jakob Bendix, Nadia Ryding - a trained stoma nurse and shop owner of CPH Femme (a shop with a focus on fashion and lifestyle products for women diseased with cancer, stoma or those who are recovering to deal with a new every-day life) and Astrid, who also blogs about her daily struggles at CPH Femme's blog. They all participated alongside with the author.

The framing of the workshop was for the participants to create two different pouches that visualize their personality in a 'mild' and a 'wild' version.

Insights

Input from Astrid, Nadia and Jakob brought up relevant dilemmas due to a personalized design approach. Jakob was the one around the table who had most experience in designing ostomy bags, and due to this, he created a wild version, though still in grey. Nevertheless, his wild edition could be a complete revolutionary approach towards the design of the pouch, as an ostomy bag designed for the moving body, and thereby shaped very differently (Figure 7 A).



Figure 7: A) Jakob's wild version; B) Astrid's mild version, for comfort and support; C) Nadia's wild version, questioning situations where the pouch should not be discrete; D) The author's wild version of a bag that surrounds and completely covers the shape of the pouch.

Astrid's mild version, in a material that reminded her of her active life as a Judo sportswoman (Figures 5 and 7B), was created in a neat style. She decorated the pouch with two laces of silk band to make it comfortable and support her personality while wearing it. Nadia's wild version could work as a fashion accessory together with a bikini or for participants in a carnival, making a lively and festive expression. Her design, as well as Astrid and Jakob, related very much to the different situations ostomy wearers face in every-day life, and by that the personalized design approach is relevant and arguable. Although, and by Figure 7D, the personalized design approach questions the existing product, to provoke an understanding of how an ostomy bag should look and be like.

In this sense, Jakob came up with some interesting feedback, saying what if we started from scratch to re-think the bag, also due to his 'wild' idea of a complete other form of a reservoir for the body waste.

A further step in the process could be to present the styles for non-wearers of ostomy products, to reflect emotions and thoughts when experiencing the different objects. Personal associations and sensory imaginations play's a huge role here, since we layer memories and connotations individually.

Concluding discussion

Designing in the area of taboo, stigma and discreteness, function is key. Inspired by fashion and textiles design, Coloplast creates products with even more appealing qualities than only function implies; involving the wearer's sense of self, changes in material and colour. One could ask if Coloplast's award winning re-design is that different from its former styles. Taking this a step

further, the workshop raised new questions. Why should an ostomy bag be discrete? Could it be a personal choice and supplement to our every-day wardrobe and mood?

The intentions behind the SenSura Mio as a piece of accessory design are contrasted by the opinion of the wearers from the questionnaire. In the analysis almost 50 % of the participants did not link the design of SenSura Mio with their identity. Nor did they think that the SenSura Mio fitted their personal preferences or that the design was of importance to them. So, despite Coloplast's goal of designing and developing appealing products, almost 50 % of the wearers responded that what was of most importance to them was functionality and that the design of SenSura Mio had to fit all. This fact could be framed as a paradox in the personalization of wearable health design – to raise another question if wearable health design is for habitual use, should it be mass-customized to also fit personal needs? Just to say, that there is a need for more cottage industries, to deal with such challenges for the wearer.

If the pouch looks like a fashion accessory, rather than a wearable health device, could it then break down the taboo and stigma?

This leads to question if Coloplast succeeded with a personalized design approach in the design of SenSura Mio. At least they opened up ideas about implementing fashion and textile design, as a starting point relating to these industries. As the paradox concludes, it is a complicated task to produce 167 different everyday wearable health devices in different size, colours, texture and material to meet the individual needs of the wearers – which leads to discuss if an ostomy bag even can be seen as a fashion accessory?

The framing of the workshop opened up new perspectives of how wearable medical devices could be designed. There was no cost price, need for feasibility or production requirements for creating personalized mild and wild versions of ostomy bags, for individual preferences. Thus, this approach facilitated a different environment for creativity and new ideas of how to develop and design such wearable health devices. This explorative and open-ended approach could be a contribution to scope personalized wearable health design as future fashion accessories for the individual.

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ⁱ <https://dictionary.cambridge.org/dictionary/english/taboo>

ⁱⁱ The term stoma refers to a surgically created opening in the body for the discharge of body wastes. Different diseases (e.g. cancer, Morbus Crohn, etc.) in the abdomen area can require an operation causing the need for an ostomy bag.

ⁱⁱⁱ <https://stomistjernen.wordpress.com/>

^{iv} <https://www.instagram.com/astridboomboom/>

^v https://www.facebook.com/pg/stomapetunia/photos/?tab=album&album_id=150041322247833