‘Supporting Sufferers with a 'hidden disability' through textile developments’

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Abstract: Raynaud’s, Rheumatoid Arthritis and Diabetes sufferers experience a ‘hidden disability’. Symptoms include painfully cold extremities and aching joints that affect their everyday activities. Through a user-centred design project, my MA laid the foundation for my current PhD work by researching the somatic needs and sensorial wants of a Raynaud’s sufferer. This paper discusses how the groundwork laid by the MA has helped to form and develop a methodology for the PhD, a participatory action research project. Which so far has identified a theoretical framework through a literature review, to question and challenge conventional priorities when designing for a person’s physical and subjective well-being. By linking creative and aesthetic approaches with advanced textile technology, the methodology will build on and test work that asserts the importance of aesthetics to create and maintain a sense of ‘self’ for the wearer, underpinned with the aim of exploring opportunities to use textile development to help sufferers ‘self-manage’ symptoms.

Keywords: Well-being; knitwear; Raynaud’s; user-centered; participatory design

Introduction

Raynaud’s phenomenon, diabetes and rheumatoid arthritis, all come under the umbrella term of ‘hidden disability’, because they are not apparently obvious to a viewer. Persons living with one or more of these neurological conditions experience symptoms such as aching joints and poor circulation that affect their everyday activities. This paper describes a user-centered design project, to create intelligent knitted constructions that enhance the physical and sensory experience of a person living with Raynaud’s phenomenon. A questionnaire, focus group and interviews with Medical Consultants, showed little attention is paid to the feelings elicited by wearing a therapeutic medical garment. The project applied a knitwear design process through participatory action research to connect the medical and aesthetic dimensions of the condition, enhancing patients’ physical and mental well-being. By bringing technologists, designers and patients together, the next phase of the work aims to identify and address patients’ un-met needs by aligning functional and therapeutic design elements with the aesthetic and sensorial issues often overshadowed by the emphasis on performance in ‘assistive’ clothing. This collective process of collaboration between all participants is at the heart of participatory action research. Baum et al (2006) explains that the participatory design process facilitates researches to create partnerships within communities leading to action of change. In this paper, the user becomes a co-creator/co-partner/co-designer at the early stage of the design process. Acknowledging a person living with Raynaud’s as an expert of his/her own lived experiences gives them the opportunity to influence design elements for the first knitted prototype. In addition, Suri (2015) states that “to design with people’s experiences in mind we need to better understand what qualities matter to the people we are designing for and the ways that design can enhance their experiences” (2015, p41). Adopting user-centered methods, I was able to collaborate not only with Raynaud’s sufferers, but also with health practitioners, the Raynaud’s and Scleroderma Association to uncover what really matters in an artefact designed for a ‘hidden disability’.

This paper presents a literature review that underpins the development of the methodology adopted in the initial phase of the research (user-centered). It will discuss a collaborative approach involving the user at the fuzzy front end of the design process, informing the design elements for the first prototype. The methods used, the results and how these translated into design (knit) solutions are than described before concluding with some reflections on how by building various collaborative relationships, I was able to carry out the methods described in this paper to uncover what really matters to a person living with Raynaud’s in relation to dress.

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To Design Beyond the Physical Symptom

Since the 1950s, designers and scholars have directed attention to the apparel needs of people with physical disabilities, designing so-called functional clothing or functional fashions. However, people with such needs do not want functional garments that are unappealing or that convey a stigmatized image. Therefore, the challenge for apparel designers is to create designs that will be attractive and socially acceptable on bodies that may not conform to typical contours, surfaces, or motions. (Lamd et al, 1992, p42).

In 1992, Lamb and Kallal introduced the functional, expressive, aesthetic (FEA) framework for apparel design education. It is a model, which does not distinguish between fashion design and functional apparel design. In 2011, O'Mahony affirmed that in the context of advanced textile or intelligent therapeutic garments for health and well-being, “the coming together of the technical and the aesthetics is key to producing materials that perform, also look good and are pleasant to handle” (2011, p19). However, there remains a need for a better understanding regarding subjective well-being, personal identity, emotional experience and social engagement when designing for garments/accessories with a therapeutic function (Bush, 2015). Great design looks beyond the usability of a product to establish an emotional bond guaranteeing a higher chance of success for a long-term subject-product attachment (McDonagh-Philip et al, 2009) and there is potential in products to generate psychological happiness as well as stimulating physiological well-being (Demirbilek and Sener, 2003).

Emotions have traditionally been overlooked in the practice of science (Groth, 2016, p27), but as DiSalvo puts it, ‘as people become more sensitive to dimensions of products that go beyond traditional aspects of usability, the need to create emotional resonance between people and products increases’ (2004, p251). To elicit an emotional response and attachment to new technology, in the context of subjective well-being, creating pleasurable experiences and a sense of ‘self’, an aesthetic dimension needs to be present with the intention of designing with a human participant for a physical function. Designers must consider the emotional needs of users alongside the usability aspect of a product as users’ needs and expectations are changing (Chapman, 2005).

Responding to this need to consider the emotional aspect of a product as part of a holistic medical intervention, I have identified a theoretical framework through which to question and challenge conventional priorities when designing for a person’s physical and subjective well-being. The research will define the potential for the aesthetic dimensions of therapeutic garments to influence wearers’ emotions about the garments whilst promoting attachment in relation to garments and accessories designed for a ‘hidden disability’. This includes work on emotional expressions and mood influenced by experience (Dewey, 1934), the role of emotions in social cognition and decision-making (Damasio, 1999), and the relationship between the emotions elicited by a design and an individual’s engagement with a product that may benefit them (Frijda, 2009).

Consequently, the project is building on literature from two research areas: - Emotion and Design: and Smart Textiles and Health. Tyagi and Goel argue that aesthetically pleasing clothing addressing fit in terms of physical comfort contributing to functional independence, enhances emotional well-being as a function of self-worth. In their research on factors affecting choice of clothing for women over sixty-five years old, they discovered three functions attractive clothing can provide for these women. It can ‘call attention to one’s good features, camouflage poor features and give a psychological lift’ (2013, p312). Reflecting on focus group conversations with Raynaud’s sufferers in the early part of the research, these three functions resonate with my understanding of the traits therapeutic dress should offer. In like manner, ‘Emotional Fit’ (Townsend et al, 2016) explores the importance of matching the emotional needs to the technical materials when designing for mature women: - women who feel neglected by the...
fashion industry. Through Interpretive Phenomenological Analysis, amalgamated with a fashion and textile design approach, the team considered both the physical shape and the emotional shape of the participants. The aim of both these projects is simultaneously to address the emotional and physical needs of women over sixty-five years old. Both are relevant to my work because of the argument they present, recognising that it is imperative to elicit positive emotion in dress for that “psychological lift”, or as Givechi and Velázquez describe it, as creating positive space necessary to ‘empower, delight and connect’ (2004: p44).

Among other work carried out in the design and emotion field is the LAUGH project, which realised the role of emotional memory in supporting the subjective well-being of patients suffering from late stage dementia, underpinned by a ‘positive design’ framework. Conversational bridges were stimulated with the aid of bespoke E-textile sensorial aprons (Treadaway et al, 2016). Designed around the individual’s life story, the aprons hold personal preferences through embellishments and embedded electronics. The principle is to promote and sustain positive emotion with a chance to connect and communicate on an emotional level with a person suffering from dementia who is socially impaired. This connection leads to pleasurable experiences and positive behaviour. LAUGH have created a ‘positive space’ (Desmet & Pohlmeyer, 2013) or, an ‘intangible essence’ becoming ‘more significant than the source’ or product itself (Givechi & Velazquez 2004, P43.), from a product experienced by all stakeholders stemming from the user’s pleasurable life experiences. These results validate the rationale for adopting the principle of designing for positivity with empathy in the health care context.

In other work, the foundation for positive emotions and or experiences, is laid by addressing the concept of ‘self’ in relation to the psychological aspects of dress, as, ‘it is our bodies that give us social presence in the world’ (Radvan, 2015, p37). Radvan’s research addresses the lack of well-fitted, aesthetically pleasing knitwear for women with a physical disability, aiming to provide ‘choice of dress’. Radvan’s project explores the expressive needs of the individual leading to empowerment. In similar context, Hall and Orzda (2013) research a product’s ability to communicate the sense of self in expressive prostheses by viewing a medical device as a fashionable accessory; it is an example of how new technology sensitively crafted can empower an amputee physically and emotionally.

There are also examples of a more reductive approach to designing for a physical condition that downplays the importance of eliciting an emotional attachment from a garment with a medical intervention. Investigating the combination of knitwear technology, medicine and Chinese acupuncture, Li Li et al (2014) looked to develop a novel therapeutic method for healthcare through dressing. The project’s aim was to replicate TENS therapy using conductive yarn, textile electrodes and a battery within a garment pleasing to the eye, providing the wearer the chance to self-manage their pain relief more effectively. At Nottingham Trent University (NTU), the concept of pain relief knitwear has seen the development of gloves to alleviate pain associated with Raynaud’s phenomenon. By integrating heated elements directly in to the structure of the glove, the aim was to create a lightweight, flexible, user-friendly and aesthetically pleasing design empowering sufferers to better manage their condition at home (Mbise, 2015).

In Stoll’s latest collection, Performance+; fashion combined with intelligent technological advantages, the NTU team have worked with Stoll to employ the same technique within a one-piece Balaclava aimed at sustaining heat surrounding an athlete’s mouth; - warming cold air before it enters the body and reaching the lungs, so enhancing performance (Stoll, 2016). NTU’s advanced textile research group are currently creating a temperature-monitoring sock for diabetics, which provides the patient and their support network early warnings of a foot ulcer (NTU, 2016). The projects results are sophisticated technology embedded within a textile artefact contributing to supporting the wearer’s physical health. The research fundamentally addresses performance of the product, only touching on aesthetics. These
are examples of designing for a condition, downplaying the importance of eliciting an emotional attachment from a garment with a medical intervention.

Gault (2016), in researching designing for health and well-being alongside a health practitioner and engineer, created products to meet the body temperature regulation needs of a diabetic. Apace with the latest innovation in Nano-technology and integration of Phase Changing Materials, the project took on board the aesthetic aspect of the knitted garment through colour chosen via the WGSN forecast website. The exploration of the aesthetic dimension was solely through colour in garments that consisted of wraps, ponchos and throws. The garments later tested on focus groups of female participants aged over sixty-five years. One of the outcomes being that the majority would not wear the garment purely for its function. Like the NTU projects, this work lacks the depth and richness of knowledge potentially gathered through a co-design approach in order to address both the physical and psychological aspects of a product with a holistic medical intervention.

Against the background of design and emotion, and smart textiles for health, further research is needed to cement the role of the 'psychological lift' (Tyagi and Goel, 2013, p312) or 'Emotional Fit' (Townsend et al, 2016) in maintaining and expressing identity, positive emotion and significance in social interaction, with regard to a ‘hidden disability’. The research to come will derive design approaches that work both for the condition by addressing the symptomatic relief and self-management needs through textile development, and with it, by considering emotional needs through a participatory process.

User Centered Design Project for Raynaud’s Phenomenon

Raynaud’s phenomenon is a common condition affecting up to 20% of the adult population worldwide and an estimated 10 million people in the UK. The disorder affects 1 in 10 women and 1 in 12 men. There are two types of Raynaud’s: - primary Raynaud’s and secondary Raynaud’s. The cause of primary Raynaud’s is unclear, as the condition develops spontaneously, whereas secondary Raynaud’s is associated with an autoimmune condition. People living with Raynaud’s phenomenon are extremely sensitive to changes in body temperature. In response to the perceived harm of cold conditions, the human body sets in motion the ‘fight or flight’ survival mechanism, saving heat by slowing blood flow to the skin through narrowing of the blood vessels, concentrating blood flow on the essential organs such as the heart. In Raynaud’s sufferers, the fight-or-flight response over reacts, narrowing the blood vessels in the extremities more quickly and extremely than normal. The restricted blood supply of an attack can be quite painful, making everyday tasks such as dressing and cooking, difficult and frustrating.

Usually triggered by cold temperatures, anxiety or stress, an attack causes the affected area to turn different colours, from white to blue, and then red as the blood flow returns. This process can be accompanied by numbness, pain, and the development of chilblains causing irritation and severe discomfort. Keeping warm is essential; not allowing the body to experience a sudden change in temperature is a means to self-manage Raynaud’s and prevent the symptoms from occurring. Keeping the body’s core warm and not just the extremities aids relaxation of the blood vessels. This inspired the title of the early phase of the work discussed in this paper, which was completed as an MA project: FASHIONING A HEART BEAT. This work engineered added warmth into knitted fabric through yarn selection, knit techniques and garment structures, deriving an artefact to protect the Raynaud’s sufferer’s body core temperature, to encourage blood flow.
Methods, Findings and Design (knit) Solutions

To be effective, design must take several dimensions of a product into consideration, including appearance, function, usability, cost, price and maintainability (Norman, 1988, p28). Traditionally, designers predict customers’ needs through relatively superficial market research that overlooks the users’ wants and needs (Popovic, 1999). By contrast, ‘user centred’ design quite often involves users during the design period, and in the testing and development period of a product (Chamberlain, 2010). Involving users at the early stage of the design process can help identify unmet needs, informing and guiding design ideas and solutions that are likely to be more effective or successful, saving on time and cost during the design and production process (Clarke, 2011). My work with Raynaud’s has applied a user centered design methodology, contacting sufferers at the early stage of the design process to inform initial design decisions (Kujala, 2003).

Suri outlines four methods that would allow designers “to fully explore design expressions that support human experience”. These are learning from data collected (primary or secondary), observing people we are designing for in context, as well as asking them to participate and of course, to try things out ourselves (2015, p.42). Therefore, the first stage was to be an extensive desktop search scoping the market for products recommended to cope with Raynaud’s and develop an understanding of how the condition works, and as Suri lays out, human interaction was the next step. However, applying a user centred design approach can be quite costly and time consuming (Moody, 2015). Given the period of the MA course (ten months) and the nature of the course (practice based), developing a collaborative relationship with the Raynaud’s and Scleroderma Association proved extremely valuable to the research. To cope with a tight schedule, research methods and the researcher/designer/author needed to be flexible, taking part in a focus group facilitated by the Raynaud’s and Scleroderma Association, rather than as part of my project. The focus group was an opportunity to participate in a group discussion, evaluating an existing product (a self-heating glove) recommended for a Raynaud's sufferer. Although I took on the role as a participator (tester) rather than an observer (researcher), this experience gave access to users’ needs and desires, empathetically providing a deeper understanding of the user’s experience, circumstance and feelings (Koutrie et al, 2009).

My involvement in the focus group merged two of Suri’s (2015) suggested methods. That of participation and trying things ourselves. Having been diagnosed with secondary Raynaud’s, I adopted an autoethnographic approach regarding my experience during the focus group to assess a self-heating glove given to each of us.

Focus Group Experience

The gloves presented for testing resembled ski gloves. Described as a self-heating glove maintaining a natural body temperature by way of the fabric drawing energy and reflecting body heat back to the wearer, with added features such as touch screen technology on the fingertips. To test the effectiveness of the glove, it was suggested we step outside the building to encourage our body temperature to drop leaving us cold before re-entering the room where the heating was turned off. To measure the effectiveness of the glove, our hands where photographed before and after with a thermal infrared app on a mobile phone. Following the focus group proceedings, I based myself in a coffee shop to reflect on my experience, writing notes to help guide further/future possible exploration.

In my case, I did not reap the benefits the glove potentially could have offered. My hands did not feel to have been warmed by the gloves and the chill that had crept over my body from standing a few minutes in the outside cold did not completely disappear. I recall putting my jumper back on and wrapping my scarf around my shoulders and neck to encourage heat to return to my body. The before and after infrared thermal image confirmed that the level of the gloves effectiveness on my hands was virtually

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non-existent. This perhaps was due to a sudden drop in my body temperature from being out in the cold and with the continuing drop in temperature in the room from lack of heating, it was difficult to warm up and produce the heat necessary for the fabric to absorb, store and reflect heat back to my hands. After evaluating the functionality of the glove, I now considered the attractiveness and sensory aspects/features. Personally, it is an item of clothing I would only adorn for certain activities such as hiking, or wear standing on the side lines of a Rugby match on a cold winter morning, hands shoved firmly inside my pockets! Although lightweight, the gloves where cumbersome restricting tasks such as writing and picking up a cup of hot beverage. In addition, my phone screen was too small for the touch screen technology.

Unstructured conversations

The Raynaud’s and Scleroderma Association (RSA) often host networking events providing information and support to their members. At one of these events, I was able to explain the aims and objectives of the early parts of this project in unstructured discussions with, several members of the society and a health practitioner. The rheumatologist iterated the importance of protecting the wrist and neck area due to main blood vessels residing close to the surface of the skin. And covering the top of the head to prevent heat loss. A recurring request emerged from the conversations with the members: - the desire for colour. One member explained she benefited from the usage of knitted gloves containing silver, but admitted to wearing leather gloves to hide their appearance. I was strongly encouraged to add colour to whatever I made. People expressed their thoughts regarding the longevity of knitwear. If they were to pay a certain price for a knitted item, they wished it would look newer for longer.

Structured Questionnaire

Leading on from this a structured questionnaire through the Raynaud’s and Scleroderma Association provided more knowledge of a Raynaud’s sufferer’s needs and desires towards current and future garments. 114 participants took part, 88% were women, ranging from 45-74 years of age. Participants preferred layering of thin garments as opposed to one thick or chunky item of clothing. Fit was important as some products were not favoured as they constricted blood circulation. Preferred products were items easy to carry and use. Battery heated gloves and insoles were considered bulky and awkward. Practicality strongly coincided with a desire for a garment to be as attractive as it is warm. The respondents believed they would benefit from warm smart trousers, wind proof knitted accessories and thermal underwear not currently found on the market. There was a wish for a glove design with more wrist coverage. There was mention of a struggle to produce heat in the first place for the clothing to keep it in.

The methods used produced an array of rich information. This led to the selection of certain elements possible to develop in a prototype within a tight period, displayed in the table titled Design Translation. The two columns highlight the key users’ desires and needs under the heading ‘Findings’: - matching them to design elements under the heading ‘Design Knit Solutions’. Brought together, the design elements converged to create the first garment prototype as seen in Figure 1. First Prototype (Knitted Jumper).

<table>
<thead>
<tr>
<th>Findings</th>
<th>Design Knit Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preventing the body from sudden changes in temperature</td>
<td>The main yarn is Merino wool, selected for its natural ability</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>helps to avoid an attack</th>
<th>to absorb moisture and move it away to evaporate in the air. A natural active fibre, which reacts to temperature changes, keeping the body warm when cold and cool when warm.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take care with the correct fit to avoid restricting blood flow even more</td>
<td>Merino wool is naturally elastic, allowing it to stretch comfortably around the body. Knitted fabrics compared to woven are more flexible in nature.</td>
</tr>
<tr>
<td>It is important to keep the back of the neck and wrists warm as main blood vessels sit closer to the surface of the skin</td>
<td>Double plush in a selected section of the sleeve panel around the wrists provides extra insulation. Likewise, the technique is located in the collar panel. An additional design consideration of the collar is in the shape of the panel. For extra protection on the back of the neck, a fully-fashioned shaped panel allows the collar to either stand up covering just the back of the neck, or roll down on itself.</td>
</tr>
<tr>
<td>Clothing should be attractive as it is warm</td>
<td>A considerable amount of time spent in the dye lab produced a fresh, elegant and feminine colour pallet answering the desire for more colour in a garment designed for Raynaud’s sufferer.</td>
</tr>
<tr>
<td>Those who could not find the garments they required wished that they were more elegant/casual</td>
<td>Design elements such as the shaping of the sleeve cuff and the collar to curve over the back of the wrist and up around the neck gave the garment a more tailored look.</td>
</tr>
<tr>
<td>Warm but lightweight</td>
<td>The garment needed to be as warm as possible with style being a key design element. The use of intarsia connected several knitwear techniques seamlessly highlighting the bespoke elegance of the garment.</td>
</tr>
<tr>
<td></td>
<td>The technique plush creates loops in the fabric creating pockets of space to capture air for insulation purposes. Knitted on a fine gauge machine the technique is refined to create a lightweight fabric soft to the touch.</td>
</tr>
<tr>
<td>Longer lasting knitwear</td>
<td>Piling or bubbling of knitwear, especially with natural fibers, occurs after a handful of wears, ageing the appearance of the knitted piece. Plating under the arms with a viscose yarn on the outside and the merino wool on the inside prevents piling adding to the longevity of the garment. This contrast in yarn and colour added another dimension in texture and style.</td>
</tr>
</tbody>
</table>
An MA course provides a platform for exploration and experimentation, an opportunity to acquire and develop new skills in design, making and research, such as the user-centered design approach presented here. This informed the design and production of a collection of engineered knitted fabric samples, and the first prototype of a knitted garment. Organising a focus group to test and evaluate the first prototype with users was beyond the scope of this part of the project, but is being addressed through further research in the context of well-being, dress and hidden disabilities within a PhD. Here, the methods used in my MA will be explored and developed further, fully recognising my role and positioning as a designer among the users, health practitioners, organisations and technologists involved.

The work so far shows how engaging with users at the early stage of the design process can inspire innovative and purposeful design. However, Steen argues that one should move away from a user-centered design towards a human-centered design approach “because the former suggests a concern for people, whereas the latter suggests a narrower focus on people’s roles as users” (2011: p45). Furthermore, Jordan contends that usability-approaches are limited and even “dehumanising, as they tend to focus on merely on the fit of a product to a person’s cognitive and physical characteristics”
Jordan argues that “pleasure-based approaches to product design can be seen as approaches that consider the all of the potential benefits that a product can deliver – those of practical, emotional and hedonic benefits” (2000, p12). Moving away from designing just products, this work has considered the hedonic potential within a garment for the self-management of Raynaud’s symptoms by complete, feeling, humans – not limited by the instrumental connotations of ‘user’. To adequately understand people’s experiences, desires, dreams, fears, aspirations and goals, my research methods need to evolve from a user-centered to human-centered through participatory action research in the context of emotional and physical well-being planned for the next stage of the project.

Conclusion

In this paper, I have discussed initial findings of a user-centered design project for Raynaud’s phenomenon. Through participatory design, various collaborative relationships developed between the designer/researcher and those living with Raynaud’s phenomenon (user), health practitioner and the Raynaud’s and Scleroderma Association (RSA). Bringing the user in at the early stages of the design process as an expert of their own experiences creates a co-design relationship. This is valuable as it addresses assumptions and misconceptions of their needs and desires before deciding on crucial design elements. In this case, to respond to desires and needs expressed by the user, I needed to address the person as a whole, rather than focus on designing for the symptoms in isolation (Dunne, 2013). As a result, the first prototype incorporated colour, texture and style to address the emotional dimension, and the enhancement of the natural properties of carefully selected yarns through intelligent knitted constructions addressed the performance of the fabric specific to the physiological needs. This participation in design information could not have been possible without the Raynaud’s and Scleroderma Association taking on the role as facilitator. Without these collaborations, the methods used to explore and support the human experience of design (Suri, 2014) would have been difficult and challenging to put in place in the time allocated for the MA course. These methods require time to build and develop collaborations, as evidenced when trying to organise a focus group to evaluate the first knitted prototype. Nevertheless, they are methods instrumental in building a foundation towards developing a deeper understanding of what a person with a ‘hidden disability’ looks for in a garment extending the effectiveness of their self-management of their condition supported through textile development.
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IDEO.ORG [Online: http://www.designkit.org/resources/1]


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