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Co-Designing for Care: Craft and Wearable Wellbeing

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Introduction

This chapter examines a neglected aspect of personal medical devices (PMDs) as products of complex design processes that function at the intersection between aesthetic and scientific agendas. Whilst these intersections have been the subject of considerable discussion since Simon's (1969) seminal work on design and creativity, the personal element of medical devices highlights more recent developments in design thinking about the relationship between designer, object and user. One approach that has gained significance in recent years has been participative design, in which users are brought into the design process to contribute to the designed outcome. In medical contexts, patients have tended to be the

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passive recipients of designed objects and services, with limited engagement in creating a user-centred functionality and aesthetic. However, engagement in the design of medical devices may have positive effects on user motivations to adherence. As such, a better and more inclusive design of PMDs may improve their use and ultimately result in better health. To demonstrate this as a possibility, a case study of participatory design is presented, in which a medical device is conceptualised as jewellery. Participant involvement in the design of an attractive and personally meaningful product met participants' desire for more personalised solutions, greater empowerment and enhanced sense of well-being. Through situating this case study in relation to design practices and theory, including the design process and 'good' design and how meaning is made through design, we open up a new approach to PMDs and medical technology, emphasising the importance of considering design. Building on this perspective, we suggest that through a co-design process PMDs might be made more personalised, and that we might find ways in which PMDs, and other health technologies, could be better designed for care through design collaborations.

Good design is essential to both appearance and performance of products. When they are easier to use, fit for purpose and attractive, they have motivational qualities; the idea of "I want to use it" rather than "I have to use it" invests a degree of ownership in the designed device. However, design refers to both the process and outcome of the activity (Walsh, 1996) and the route to participatory design is an evolutionary one. Explaining design, and what designers do, defines the possibilities for patient engagement through designer problem-solving, 'know-how' and the designed outcomes. When design practices combine with an increasing awareness of the importance of person-centred healthcare, they form a compelling focus for research (Golubnitschaja et al. 2014).

The argument is extended by the US National Institutes of Health. In order to balance cost reduction with improvements to health and healthcare, they proposed that medicine should move away from "one size fits all" therapies to become more predictive, pre-emptive, personalised and participative over time (National Institutes of Health 2008). The development of service and interaction design and the

proliferation of sophisticated yet affordable PMDs facilitate this approach. Some personalised devices (e.g. glasses and hearing aids) have been used for many years, but they increasingly include more complex technologies (e.g. blood pressure monitors) that enable patients to independently monitor their own health. Such devices clearly provide opportunities to gather and communicate personal information. However, it is less clear how the appearance, functionality or symbolic meaning of technologies contribute to personalisation and individualised experiences.

Within this spectrum of devices, the provision of personal orthotics presents a particular challenge. The correct supply and fit of orthotic devices can be a major factor in the management of a health condition and in preventative care (HEC 2009). These are addressed by NHS England's (2015) guidance for understanding patients' needs and the recommendation of a ten-step process. Whilst most of these steps focus on service provision and transformation, others focus on patients and devices and include the need for devices to be comfortable and provide appropriate support and accurate fit, a choice of high-quality providers, and the need to be cosmetically acceptable, in particular for image-sensitive younger people. These guidelines point towards a significant change for orthosis provision that improves both patient satisfaction and adherence.

Since orthotics are orthopaedic devices for immobilization, restraint or support of the body (Glanze et al. 1990), personalisation is required to offer the close fit necessary for them to function appropriately, and to allow people to feel an emotional attachment towards them, as they would towards other worn objects or 'wearables' that match their sense of fashion or style. Therapeutic user engagement addresses this challenge through opportunities to develop craft techniques for personalisation and, in so doing, highlights the relationship between designers and users, design practices and design thinking.

The crafting of splints in particular has a long historical connection. Twentieth-century European wars provided the catalyst for the development of both materials and techniques. In the First World War, sculptors and woodcarvers applied craft sensibilities to explore the use of materials such as papier-mâché, leather and textiles, developing new

forms of fabrication (Llewellyn 2010). During the Second World War, furniture designers Eames applied their plywood-forming technology to leg-splint design, further demonstrating how the crafting of materials, methods and anatomical knowledge has contributed to personalised, well-fitting devices. And whilst craft has influenced splint-making, so the process of splint-making has also influenced craft and design culture (Pullin 2009).

The personalisation of orthotic devices, the use of craft techniques and interactive design principles may create a new model for developing effective treatments. Our case study demonstrates how participants with Ehlers–Danlos Syndrome-hypermobility type (EDS-ht)¹—a condition which requires the use of splints—felt about wearing conventional splints, and how engagement in the design of different splints enabled them to create better-fitting and more personally meaningful devices. In order to explore a design approach to PMDs, we first situate PMDs within design theory, drawing on ideas of what constitutes ‘good’ design, how meaning is made through design, interactive approaches, and how it might be possible to design for care.

Design

The development of orthotics demonstrates how design processes and outcomes themselves are subject to change both in activity and interpretation. Reflecting on the development of design, Buchanan (2001) describes places or placements as areas of discovery and invention that characterise the practice of design. They demonstrate new ‘orders’ of practice and research as a way to answer new project and societal demands. Buchanan argues that design’s trajectory has moved from ‘symbols’ (graphic and communication design) to ‘things’ (product design), ‘interactions’ (interaction design) and finally ‘systems’ (environment and system design). These orders are not rigidly fixed, but represent the growing scale and complexity of design interventions. The definition of design that emerges is by no means straightforward but necessarily captures the relationship between the creative process and realised solution as ‘the intentional solution of a problem, by the

creation of plans for a new sort of thing' (Parsons 2016, p. 11). In this, design distinguishes itself from craft, which draws on the development of traditional skills and the application of standard rules to materials (Parsons 2016).

From an object perspective, PMDs can be considered as designed products that demonstrate a relationship between form and function. Functionalist approaches developed the principles of functional aesthetics, emphasising geometry, precision, simplicity and economy in the design of products. Design should be from the 'inside out' so that the form of a product follows from its function, an approach later summarised by Mies van der Rohe, one of modernism's leading proponents, as 'less is more'. Arguably, in this tradition, functional form was realised as a styling feature, a fashion for nothing, much as other movements were associated with style through different forms of ornamentation (Lambert 1993). In contrast to this minimal European approach, styling features were very much a part of mid-twentieth-century American modernist design. These designers emphasised the product's exterior in response to commercial demands for the creation of product appeal. Raymond Loewy famously pronounced that 'ugliness does not sell' and created streamlined styles favouring non-functional, aerodynamic shapes—an approach that remained influential to the 1960s (Ulrich and Eppinger 2012). However, a defining feature of both approaches is their concern with new materials and, with them, new possibilities for design.

Good design came to be explicitly stated in another way, through the practices of industrial design and new product development (NPD). Of enduring influence are Dreyfus's (1967) five critical goals to achieve utility, appearance, ease of maintenance, low costs and communication, in which the visual quality of products communicates corporate design philosophy and mission. In this way, industrial product design came to be considered in two important dimensions: first, ergonomics, which encompasses all aspects of a product that relate to its human interfaces, and includes novelty of interaction needs, maintenance and safety issues; and second, aesthetics, considerations of whether visual product differentiation is required and the importance of pride of ownership, image and fashion (Ulrich and Eppinger 2012). This approach

advanced consideration of the user and user needs in respect of products, albeit defined by the designer and the organisational environment.

Meaning-Making Through Design

Whilst PMDs can be considered within the product order, the expansion of design into a broader problem-solving activity is reflected in the possibilities of approaches that consider design in terms of meaning (Brown 2008). With these approaches, objects are shaped by human intentionality and human-made things are dependent on intentions to exist, and thus part of the language that design can create and shape.

Krippendorff's philosophical and semantic approach defines design and designers' work as a matter of creating meaning rather than artefacts (Krippendorff 1989, 2006). In this account, meaning is a cognitively constructed relationship that selectively connects features of an object and features of its context into a coherent unity. Objects must always be seen in contexts of other things, situations and users, including the observer themselves. Thus, meaning not only signifies a product's basic functions and aesthetics, but also carries an emotional and symbolic value, bringing a product message to the user (Krippendorff 2006). In PMD contexts, it is pertinent to consider design as making sense of things: people and very personal items, their relationship to who gave them, and reminders of the giver. Wheelchair design, for example, offers the opportunity to explain design-inspired innovation, meaning and how design systems functions. In the design process, the wheelchair can be thought of as an extension of the self and a means of self-expression, as a physical object but one with implicit messages. The product not only signifies its basic functions and aesthetics but also carries an emotional and symbolic value with a set of symbolic meanings for both the user and individuals observing its use. The product acts as an extension of the human body and mind by giving the user both independence and identity. Design is important as it allows for new perspectives from the beginning and through the whole process of product development (Utterback et al. 2006).

Interaction Design

Considering design as form and function in context allows products to be seen as objects; a meaning-led approach extends its connection with users. Buchanan's third order of design moves from object to interaction, an approach that embraces human-centred design. In these accounts, the user is a resource and design is focused on understanding and delivering what users want. It sees designers as part of a wider group of agents in the process of co-production or co-creation. It also accounts for changes in understanding the process of designing, suggesting that we are constituted in relation to the world not only as thinking subjects but also as bodily beings (Schön 1983).

With interaction design, the designer becomes an actor who is able to listen to users and facilitate the discussion about the design process. This approach can be communitarian in focus or applied to individual service encounters (e.g. an individual patient in a hospital) in which the user is a bringer of capability. In service design, where users are engaged in the design process and outcomes, a basic requirement is to find a balance between what designers try to fix and what is to be left free.

To account for this interactivity between design and user, models of user-engaging design have emerged. Sanders and Stappers (2008) define two mindsets: 'expert', in which users are subjects and reactive informers; and 'participatory', where the users are partners and active co-creators. User-centred design is therefore distinguished from participatory design by the active engagement of the user. Participatory co-design sees designers creating solutions with people from a community and recognises that local value chain actors can leverage local knowledge. It can also lead to innovations that may be better adapted to their context and be more likely to be adopted, since local people have invested resources in their creation (Brown 2008). With co-creation, users have a proactive role and should be involved at every stage of design development and as early as possible (Keränen et al. 2013).

These perspectives define a design agenda for PMDs. Designing has moved from a focus on the designer's creativity directed towards an object to a broader range of concerns and activities. The ability to relate

form and functionality to products remains an important but not an exclusive aspect of designing. It is difficult both to design and to appreciate design without paying attention to its meaning. Moreover, the designer as facilitator or force for change, working with users and participants, has expanded the role and possibilities for design. The next section further develops these perspectives on user participation and co-creation, and by focusing on the design of PMDs in the health sector, it introduces wellbeing as an objective of participative design.

Design for Care

Contemporary healthcare is characterised by an increasing array of medical devices for diagnosis, prevention, monitoring and treatment of disease (World Health Organisation 2003; EC 2001) and more specifically the management of injuries and control of conception (Global Harmonization Task Force 2005). Wearable medical devices placed on our bodies play a role in our personal and intimate worlds, influencing our everyday lives and self-perception. Faulkner (2008, p. 27) discusses the depth and reach of their influence and explains that:

Medical devices enter into our intimate and family relationships, into our understandings of health and disease, our values and beliefs, our practices of looking after our own health, as well as our experience of healthcare systems and healthcare professionals' work.

As a subset of medical devices, wearable medical devices are worn objects. They are characterised as autonomous, usually non-invasive artefacts that are located on the body to perform their medical purpose (Fotiadis 2006). This requires devices to operate in a range of social, non-medical settings for a variety of activities in which the wearer may engage in their everyday lives, and to be wearable in all these settings.

Further research has focused upon orthoses as a specific form of wearable medical devices, also known as splints, braces and supports (Fess et al. 2004). Generally, splints function to immobilise, restrain and

support the joint and are designed by hand therapists and occupational therapists based in hospitals. One important issue affecting the efficacy of splints is the low rate of patient adherence to their prescribed use. As found with other PMDs, whilst many people choose to wear these objects as prescribed, for others it is evident that the design of wearable medical devices within the traditional biomedical model creates artefacts that can lead to low adherence and dissatisfaction.

There are a number of reasons for low splint adherence. Paterson's (2013) review of the literature identified important problems with wearability, including: inappropriateness for the patient's condition; difficulty to remove and put on; issues with comfort and fit; hygiene; and perceptions of both impracticality and undesirability. Furthermore, splints may be socially and emotionally unacceptable. Other researchers have reported issues of style, aesthetics and cosmesis affecting patient adherence (McKee and Rivard 2011). In order to address this, McKee and Rivard suggest that an approach which situates health within a biopsychosocial model might be a productive direction for orthotic intervention.

The biopsychosocial model of health (BPS; Engel 1977) encompasses psychological, social and biological factors. In addition, we might think of health as an ability to adapt and to self-manage (Huber et al. 2011). More specifically, health requires 'the sufficient competence of a person to cope through self-regulation with any stressful disturbance on every system level' (Egger, 2013, p. 26). In these ways, it challenges the dominant biomedical model, with its focus upon the biological body (Fox 2012). By adopting a personalised treatment approach towards the patient, the BPS model provides versatility for care and opens up a broader consideration of wellbeing within the design process.

These understandings are also taken up in participatory medicine, a form of co-operative healthcare in which patients, healthcare professionals, caregivers and other stakeholders are actively involved in the management of an individual's health (Gruman and Smith 2009). In this model, an important factor is the relationship between the healthcare professional and patient and the sharing of decision-making with the aim of patient concordance rather than compliance (Mullen 1997).

Table 11.1 Fifteen guiding principles proposed by McKee and Rivard (2011)

• A patient or client- centred approach	• Optimise comfort
• Psychosocial factors	• Cosmesis
• Optimise body structure and function	• Convenience
• Enable activity and participation	• Use ‘less is more’ approach
• Well engineered	• Provide education
• Optimise usability	• Monitor and modify
• Provide choice	• Evaluate outcomes
• Minimise harm	

This move towards participatory, personalised medicine is similar to the shift of focus from object-centred to experience-centred design (Sleeswijk Visser 2009). It highlights a design for care approach and its effectiveness through participation in the design of new services and medical devices (Jones 2013).

McKee and Rivard (2011) propose fifteen guiding principles to undertake such a design process (Table 11.1). These support McDonagh’s (2006) assertions that there is a need for a balanced approach to both functionality and supra-functionality, which is achieved by designing with rather than for people (Weightman and McDonagh 2003).

Although these principles are far reaching, they do not consider the fundamental reasons why people choose to wear objects on their bodies. In this respect, a craft sensibility firstly provides insights into the cultural and personal significances of wearing objects through the exploration of material and process (White and Steel 2007). Secondly, this approach extends the understanding that the experience of wearing a medical device is similar to the experience of wearing jewellery:

...the sensation of touch on the body is pre-eminent, but movement and gesture, signal and message also become active participants in a web of visual, physical and psychological elements. (Watkins 1999)

This intimate relationship between the worn object and the wearer’s sense of identity and wellbeing is often overlooked by research into wearable medical devices. For George Simmel, the jewellery-object

performs or communicates the wearer's identity to others by singling 'out its wearer, whose self-feeling it embodies and increases at the cost of others' (Frisby and Featherstone 1997, p.207). Whilst personal identities and their maintenance are integral to individual wellbeing (Bostrom and Sandberg 2011), the implications for wearable medical devices and patient adherence are considerable and deserve further consideration. Contemporary jewellery provides a framework in which to locate and investigate their design.

Contemporary jewellery design is a movement originating from the 1950s that considers and challenges the themes and properties of jewellery (Skinner 2013). It acknowledges that the relationships between object, maker, wearer and viewer provide continual communication and interpretation of aspects such as identity and cultural values through semiotics and material use (Mazumdar 2014). As a craft, contemporary jewellery can be presented as both an approach and an attitude (Adamson 2007), and it is posited that this approach provides a new direction for co-design and design for care creating the therapeutic jewellery solutions described in the case study later in the chapter.

The similarities of jewellery and wearable medical devices begin with their characteristic of being worn or carried on the body, where they can play 'an active part in constituting the particular experience of the self, in determining what the self is' (Miller 2010, p. 40). Whilst jewellery is crafted to appear distinctive and (in the case of bespoke pieces) also crafted to the needs and desires of the individual client, the wearable medical device is designed with a medical aura that only considers the medical needs of the client. The value of the medical device is measured by its ability to restore or maintain the biomedical health of its wearer, whereas it is the emotional and material value of jewellery that is often the focus of wearability and meaning for the wearer.

Between wearable medical objects and jewellery lies an intersection in which therapeutic jewellery is located. This space enables the creation of therapeutic jewellery, a hybrid object that applies a craft approach to develop wearable objects that are aesthetically pleasing and

emotionally engaging, potentially leading to improved adherence. In this respect, biomedical considerations are still important but the psychosocial aspects of wellbeing are also incorporated into their design. This therapeutic approach embraces a holistic consideration of what it means to be human and to wear objects on the body, alongside medical objectives.

A synergy of design approaches that encourage the wearer to adhere to their prescription may thus be proposed. These approaches are embedded within the biopsychosocial model, in which biomedical diagnosis is just one aspect and participatory design is an integral part. This model is interwoven into a design for care approach, where craft is acknowledged as a vehicle to construct meaning and offer dignity to people's lives. We locate the participatory and craft design of splints and other wearable medical devices within a contemporary jewellery framework that focuses on the exploration of the richly human aspects of health and wearability. The impact of wearable medical devices on the wearer can then be considered through the identification of the qualities and associations of both jewellery and wearable medical devices, thus highlighting the limitations of traditional medical device design. Here, a third approach (co-design for care) is developed to create therapeutic jewellery, hybrid objects incorporating the philosophies of craft and medical knowledge. As Jones (2013) explains:

Designing for care brings a holistic and systemic design perspective to the complex problems of healthcare. Services have been already improved by designing better artefacts, communications, and environments. What is missing is the mindset of professional care in designing for people, practitioners, and societies. (p. 8)

Consequently, these design approaches incorporate a caring design ethic (Jones 2013) towards health-promoting artefacts. The ethic requires designers to adopt the role of healthcare professionals and to consider how design processes and outputs best promote all aspects of patients' wellbeing. This ethic is promoted through the selection of participatory

and empathic design research methods to increase an understanding of people's everyday lives. Empathic design enquires about lived experience, with the aim of understanding the people's authentic perspective (McDonagh 2006). By using methods that develop empathy, the designer is able 'to become closer to the user through respectful curiosity, genuine understanding, and suspension of judgment' (McDonagh et al. 2009, p. 310). Participant engagement in generating design solutions arises from the personal crafting of objects. Their qualities, functionality, comfort and so on, when combined with their meanings, provide exemplars of processes and outputs that are readily accessible to others. Furthermore, data regarding the supra-functional needs of the user, which include the emotional, spiritual, social aspirational and cultural aspects of relationships with products, allow for object design to enable people to engage with objects at both rational and emotional levels (Chapman 2005).

These participatory processes help to overcome problems of self-selection bias, where the decision to participate can be perceived as an opportunity to promote awareness of interests, activism or 'setting the record straight'. The use of craft techniques focuses participants on the creative and aesthetic qualities of the designed orthotic object, as a means of engaging with the process of personalisation rather than its verbalisation. Further, they help to overcome problems of tokenism, or perfunctory engagement with a small number of patients. Participative design necessarily requires small groups and purposive sampling techniques that can be applied to specific medical conditions.

These perspectives also demonstrate how healthcare is evolving through the adoption of a design for care ethos. The growing acceptance of patients as equal partners creates an environment for design interventions and enables the holistic design of medical objects. In the context of wearable medical devices, therapeutic jewellery is a co-designed person-centric health device. These aspects are explained more fully in the following case study, which demonstrates generative design methods to inform and inspire therapeutic jewellery design to meet the needs of patients.

Case Study: The Craft of Wearable Wellbeing

The case study presented here was a practice-based project to research the design of therapeutic jewellery. This project was informed by the designer-researcher's experience of wearing orthoses to manage hEDS-ht. These orthoses were worn long term to manage pain and to immobilise the joints after dislocation or soft-tissue injury. Orthoses are commonly used by hEDS-ht patients to manage the condition, alongside a prescribed physiotherapy regime. This entails wearing a range of different orthoses for the affected joints throughout the day and night and over a lifetime, for the range of acute and chronic issues that the hEDS-ht patient experiences.

The research agenda hypothesised that designing within the biomedical model results in wearable medical devices with a medical register and low patient adherence. Consequently, a biopsychosocial design model was proposed for the design of a new hybrid artefact: therapeutic jewellery that promotes all dimensions of the wearer's wellbeing.

The case study synthesises design approaches, using principles of generative design, participative design, contemporary jewellery design and digital fabrication within a biopsychosocial health framework. The aims were to explore methods, practices and artefacts that support design for care processes in order to improve the design and services of these objects. This account focuses upon three aspects of the design process: the development of co-design methods for the PMD; implications for design arising from a hybrid design approach; and the conceptualisation of a co-designed orthosis.

Co-Designing for Care

Generative design research is carried out at the front end of the design process (Sanders and Stappers 2012). The project comprised a series of elements; the objectives and rationale for each activity are outlined in Table 11.2. An initial scoping exercise was promoted by HMSA (Hypermobility Syndromes Association) to its membership, where they were directed to respond to via email or social media (Twitter

Table 11.2 Elements of the research project

Element	Description and instructions	Objectives
Scoping study	<p>Questionnaire</p> <p>Series of 9 questions regarding wearing orthoses</p> <p>Further discussions on Facebook and by email</p>	<p>To test hypothesis that wearers are dissatisfied with available designs, which leads to low adherence</p> <p>To explore themes arising from the data</p> <p>To generate information to inform workshop</p>
Sensitising pack	<p>Sent 2 weeks before workshop</p> <p>Workbook that includes short daily activities</p> <p>Photography tasks</p> <p>Questions regarding the wearing of orthoses</p> <p>Clay model of something precious to the participant</p>	<p>To immerse workshop participants in making observations and reflections</p> <p>To allow participants to address feelings and thoughts about topic</p> <p>To gather further data regarding the experience of wearing orthoses</p>
Workshop exercise A:	<p>Create a collage box showing participant's wellbeing experience.</p> <p>Using a cardboard box template, choose from 100 images (both abstract and concrete) and 20 words (expressing feelings and emotions) to make a collage covering four sides of the box</p> <p>Individuals to share story with the group</p>	<p>To generate data that:</p> <p>Improves designer-researcher empathy</p> <p>Informs aesthetic decisions</p> <p>Explores meaning-making</p>
Workshop exercise B:	<p>3D model of dream device of the future</p> <p>Choosing from the range of crafting materials provided, to create a model of your dream wearable medical device</p> <p>Participants to share each model with the group</p>	<p>To generate data that:</p> <p>Informs the further design process</p> <p>Identifies key themes and issues regarding orthoses</p> <p>Increases empathy</p>

(continued)

Table 11.2 (continued)

Element	Description and instructions	Objectives
Analysis of data	<p>Thematic analysis</p> <p>Metaphor analysis: Image schemata (Johnson 1990)</p> <p>Visual analysis</p> <p>Methodological triangulation</p>	<p>To analyse data:</p> <p>Note patterns, themes & clusters</p> <p>Making metaphors</p> <p>Making contrasts/comparisons</p> <p>To assume a coherent understanding of the data</p>
Design concept	<p>Devise possible ways forward based on analysis of data:</p> <p>Design artefacts:</p> <p>Scanned CAD of wrist</p> <p>Collection of wrist splints as therapeutic jewellery:</p> <ol style="list-style-type: none"> 1. Desktop 3D printed 2. Traditional jewellery techniques: using silver and wood 3. SLS 3D printed <p>Web-based digital health project</p>	<p>To explore the possibilities that technologies offer to improve the design of orthoses and the design process for recipients</p> <p>To develop a range of wrist splints within contemporary jewellery framework</p> <p>To explore idea of digital health project with open source designs available</p>

and a Facebook project page open to comments). This generated data from respondents that supported the research hypothesis, and which informed the design of a sensitising pack and a workshop. The aim of the sensitising pack was to allow participants to explore the scope of the topic and consisted of a workbook with short daily tasks that included taking photos of objects and settings, and describing aspects of their personal splint use.

This process was subsequently developed in a workshop, where participants became co-partners with the designer-researcher. A group of between four and eight participants enabled the workshop facilitators to pay attention to every individual (Sleeswijk Visser et al. 2005). Seven women were recruited for the workshop with the support of HMSA. These women all have hEDS-ht and long-term experience of wearing orthoses. They were motivated to take part due to their dissatisfaction with wearing orthoses and their desire to engage with the design process in order to create devices with more wearability. The workshop was women-only in order to focus on wearable solutions that incorporated notions of adornment for women, and to create a safe space for women to discuss sensitive issues (i.e., body image). At the time of the workshop, half of the participants were working whilst the other half were medically retired due to hEDS-ht. The women ranged in age from the twenties to the early sixties. This research was seen as the opening trial in a series of studies to research the experiences of patients with different medical conditions who wear wearable medical devices and to investigate patient involvement throughout the design process.

The principle behind generative techniques is to allow people to make designerly artefacts and individually share stories about their objects (Sleeswijk Visser et al. 2005). Two exercises were organised for the workshop, both using craft-based representational strategies. Participants individually created a collage and a 3D model that they then shared with the group. This employed a craft approach on the basis that craft and art practice allows for the ideas of participants to be embodied and given form in the model-making process (Sullivan 2006), and on the basis that ‘by connecting people on emotional and visceral levels, artistic forms of representation facilitate empathy’ (Leavy 2015,

p. 14). The qualitative data generated was then analysed to inspire and inform the concept design of orthotic wrist splints.

The first exercise generated data regarding participants' experiences of their own wellbeing and illness. Participants made an individual collage in a cardboard box form, using a collection of 100 images and 20 words to describe their own feelings and experiences towards wellbeing. On completion, they shared their models and personal narratives with the group. Collage is a widely used technique in qualitative research (Leavy 2015), helping the collage-maker access intuitive knowledge and enabling communication on a metaphorical level (Butler-Kisber and Poldma 2010). The second exercise entailed participants considering their 'dream health device' and producing a 3D model, again sharing their models with the group. This enabled them to explore solutions for orthoses and accessed their 'tacit' knowledge (Polanyi 2002) regarding these artefacts.

Implications for Design from the Participatory Workshop

Themes identified in the scoping exercise and sensitising pack were supported through analysis of the data generated by the participants' 3D models of splints within the workshops. These data included the transcripts of participants' discussions regarding their models and the researcher's visual analysis and assessment. In discussions, participants demonstrated their expertise regarding wearability by identifying the design factors that influence the wearability of orthoses. These were identified as: fit; function; style; aesthetics; materials; method of making; emotional engagement and meaning (Fig. 11.1). Each of these factors impacts upon the wearer's adherence to the device and needs to be addressed if wearability and adherence are to be improved.

Participants felt conflicted between wearing orthoses and feeling that these artefacts were socially undesirable. As one respondent commented:

I don't want to be defined and judged by 'granny beige' splints and surgical looking supports... I am a young woman who happens to have a disability - that's a side note. I also happen to have a very definite sense of style and that WILL translate to the very things that are meant to make my life easier and better, so help me!

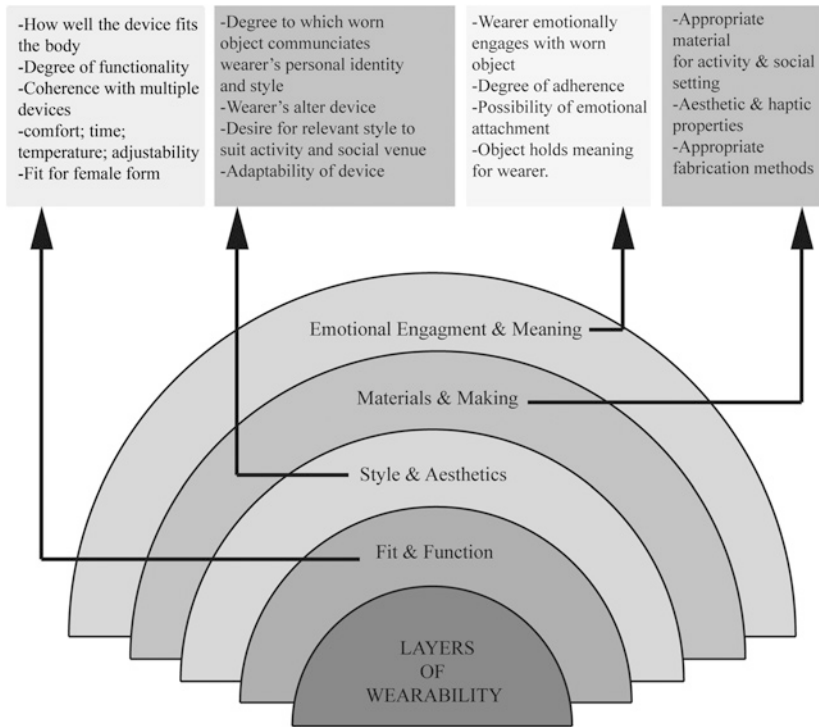


Fig. 11.1 Design factors influencing orthotic wearability

Participants were very clear about the effect of wearing orthoses. One commented on finding a device that she could wear to a social occasion: 'For 2 hours I regained my "mojo" and felt like me'. Another summed up more negative experiences:

Generally, very little thought goes into them in my experience, for people who have to wear them constantly. Sure, if you break your wrist and need to wear a splint for six weeks you can put up with it being hot and sweaty and looking horrible, but not if you have to wear it day in and day out.

Their awareness of material properties of objects worn on the body highlighted issues of breathability and thermoregulation, with many comments mirroring one participant's observation that 'the material

not being hot and clammy would be good, making it look more like an accessory than a splint, and breathable'. Aesthetic qualities were also commented on. Whilst Velcro was seen as useful, it was also disliked because it 'catches on things, ruining the splints or other clothing and scratching skin'.

The workshop generated a range of insightful data that demonstrated this group's negative perceptions regarding the poor wearability of orthoses and the accompanying negative impact this had on their sense of wellbeing. Through participants' accounts, current orthoses emerge as 'ugly', 'sweaty', 'unstylish', impractical and difficult to use over the long term. Both cosmetic aspects and the comfort of day-to-day use are addressed through such understandings, which made participants unenthusiastic about, and less likely to use, the medically prescribed orthoses they had been given. Whilst these medical orthoses may 'work' physiologically to support the joints, if their poor design negatively impacts on wellbeing and frequency of use, their overall success in improving health might be more questionable. The feedback from participants points to a need for design to develop devices that people can easily engage with emotionally and that they can perceive as meaningful in their lives. To this end, designers need to consider how it looks and feels on the body, how it makes the wearer feel, and how it fits into their world. Materiality is the key in this respect, with a strong need for materials that perform well on the body and do not create the sweatiness and smell that some complained about. Whilst people want the device to function appropriately and fit well, the important design aspects for these artefacts are those relating to more intangible wearability factors of personal style, emotional engagement and meaning, and it is in these areas where contemporary jewellery design can propose stylised solutions. Orthosis design should be considered in the context of self-identity and style. Consumer behaviour in fashion retailing demonstrates not only instrumental intentions to purchase but also emotional ones, in which choice, contemporary styling and endorsement through many media have major roles. In brief, the findings highlight the importance of holistic solutions and a transdisciplinary approach to orthotic design.

Developing Co-Designed Orthoses

The research subsequently moved into the conceptualisation phase (Sanders and Stappers 2012), generating a series of relevant concepts inspired by the research insights. The designer-researcher approached the design of therapeutic jewellery in an emergent manner, engaging with the source material through a reflective practice that explored design through drawing, models and the investigation of material qualities. She began by creating a collage using those images and words most used by the participants. The themes of 'freedom' and the ability to choose paths were important to workshop participants and suggested their desire for a range of choices when it came to orthoses available for them. It was decided to explore how technologies could best be employed for this purpose whilst addressing the layers of wearability, and, importantly, considering how these artefacts could promote the emotional engagement and meaning that jewellery ideally creates in the wearer. The two popular images that participants used in their collages were 'Amazon Warrior' and 'Wonder Woman', and the frequent uses of the word 'strength' were in direct opposition to the feelings of loss, chaos and brokenness that participants experienced. These were used playfully by the designer-researcher to inspire and generate designs to be worn by the two archetypes of Amazon Warrior and Wonder Woman in the twenty-first century. The image of a gift proved popular, and the maker considered how the orthoses could be considered, similar to jewellery, as gifts. These approaches to the data demonstrate craft functioning as a vehicle to construct meaning, whilst offering substance and grace to people's lives (Metcalf 2002).

A series of wrist-splints-as-therapeutic-jewellery were then devised, embracing a range of digital and analogue technologies used in contemporary jewellery making. As a creative and craft process, the designer employed 3D technology and collaborations with silversmiths and a cabinetmaker to achieve designs using 3D printing materials alongside a collection using silver and wood. Techniques include measuring the wrist dimensions and fabricating the device using traditional bench techniques, where silver is manipulated using rolling mills and

hammers. Digital technologies were used, including scanning the wrist into a CAD programme and designing the device directly onto the wrist model, and then 3D printing the device. The first collection of designs was fabricated by a desktop 3D printer (Fig. 11.2) to demonstrate the possibilities of using domestically available technologies, whilst a second collection used SLS 3D technology. A third collection was created using traditional jewellery materials such as silver and wood (Fig. 11.3). The devices were custom-fitted to the designer-researcher's own wrist. The ability to provide a perfect fit by both digital and analogue methods demonstrated the ease by which personalised orthotics can be fabricated.

In addition, a digital health project was proposed, offering a web-based service for wearers of orthoses. Open designs will be displayed within a digital library on this site for others to access for printing and to further develop the designs. The project would work as an open design project where the designer becomes 'a database designer, a meta-designer, not designing objects, but shaping a design space in which unskilled users can access user-friendly environments in which they can design their own objects' (De Mul 2011, p. 36). The approach includes



Fig. 11.2 Fresh Embrace, desktop 3D printed orthosis (Photo credit: J. Senior)

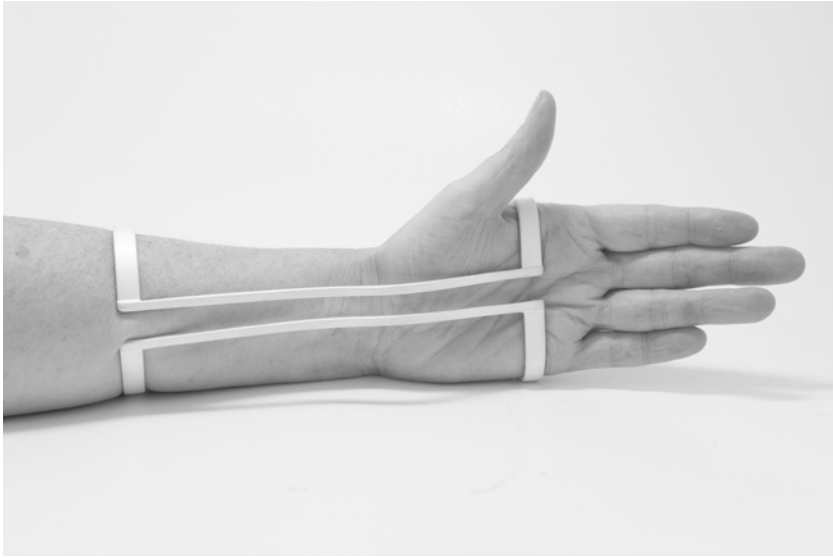


Fig. 11.3 Minimum wrist device (silver) (Photo credit: J. Senior)

the use of scanning technology that can scan body parts and import the data into a CAD programme. Designs can be then adjusted for an exact fit for each person with the wearer also choosing from a range of materials and finishes.

The design of these artefacts with craft sensibility seeks to provide functionality along with an ability to express human values (Risatti 2009). As such, the crafted object is both theorised and personalised through a radical and innovative process (Yair et al. 2001; Adamson 2010), and embraces a definition of contemporary jewellery in which ideas are served by materials and skills (Skinner 2013). Furthermore, the digital health project empowers patients to co-create personalised artefacts, whilst remaining engaged in the design and production processes.

Reviews of the collections have been positive with The Orthotics Campaign (2016) commenting that the work is 'exciting and creative'. When the 3D printed work was exhibited, viewers recorded how 'stylish', 'funk' and 'upbeat' the devices were, with some asking if they could be worn without a medical prescription. Healthcare professionals such

as occupational therapists also responded positively, recognising the potential for transdisciplinary design teams with the hope that the project will be further developed.

The original research respondents and participants were invited to review the collections, and their comments endorsed the potential of such devices. One commented:

Having some sort of control over the devices, choices, supports etc. that help improve my quality of living daily gives me back a sense of self and sense of respect and, if people have that, they are less likely to become depressed and spiral downwards physically and mentally.

Another observed that the personalised approach was empowering:

Thank you so much for this, I'm a HUGE advocate of empowering people through choices and being a disabled young woman, I have felt 'weak' and 'visible' (and also 'invisible' at times) when out and about in what can sometimes seem like a huge, flashing 'look at me' set of NHS beige-ness.

These comments are representative of the positive feedback that was received. Indeed, the only negative comments related to personal tastes and device needs, which further support the need for a person-centric approach that incorporates the full range of wearability factors. This reflects the need for a shift in perspective for orthosis design away from a medical model to a social model of prescription (Pullin 2009).

Co-Design for Care

The design for care process employed by this research develops a therapeutic design approach that becomes a new and powerful addition to co-design. It presents possibilities for enhancing patients' agency in their

healthcare by enabling them to articulate their expertise in wearing medical objects and by engaging them in applying tacit knowledge to craft objects that address the eight layers of wearability (Table 11.2). Creating objects that incorporate qualities of jewellery such as preciousness and desirability may be particularly attractive to women, but its focus on detail and the opportunities to create personalised and meaningful objects that people want to wear has cross-gender appeal. Therapeutic design provides new processes for participation building upon the co-design approach and foregrounding the importance of wellbeing as an outcome. This approach offers solutions to achieving the service criteria defined by the Associate Parliamentary Limb Loss Group (2011) for comfort, choice and cosmesis (the preservation, restoration or enhancement of physical appearance). Since research respondents were concerned about the lack of fast and efficient access to ‘right first time’ devices, a service provision that employs cheap and effective digital technologies to fabricate personalised solutions could well address these issues. This approach is supported by the Orthotics campaign (2014). Interestingly, there are also developments in the private sector, such as Andiamo (2016), set up by e-patients, who aim to deliver a 3D printed medically effective orthosis within 1 week, alongside an advanced clinical service.

PMDs provide a valuable focus for the exploration of design principles and practices, demonstrating an established commitment to functionality whilst increasing understanding of engagement with the user. Design aesthetics have been discussed in terms of form, in particular for products and their relationship with functionality. In commercial design, products must always have sales appeal; appearances are targeted at markets of potential consumers who have awareness of a very wide range of well-designed products. PMDs can draw on this commercial appeal, not least as publicly funded healthcare gives way to more mixed models of private–public partnerships. Nevertheless, they challenge notions of form, style, and design as both process and outcome in order to stimulate reflection on the increasingly diverse processes of design. Creating or facilitating meanings of PMDs by their users is an important and neglected consideration in their design. It extends the designer–object relationship into one of the co-creative processes with users. Established models of PMD design contribute to reduced wearer

adherence; consequently, alternative approaches are desirable. The case study presented above demonstrates how a biopsychosocial model can be used to contextualise new ways of designing orthotics with positive outcomes. It highlights the personal experience of the medical device, how it is sensed, and its contribution to social wearability and identity. As a result, participation in PMD design enables patients to be more aware of their wellbeing, adhere to the use of devices and be more engaged in the personalisation of their healthcare. We suggest that design, as well as use, allows individualised health technologies to become ‘personal’.

Note

1. All workshop material used in this chapter was gained with informed consent and is used with permission.

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