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Co-creating narratives: an approach to the design of interactive medical devices, informed by phenomenology

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Abstract: This paper attempts to articulate a philosophical underpinning, an *attitude*, with which to approach the design of interactive medical devices. This exploration is undertaken through drawing upon and connecting ideas from relevant discourses within the; medical, human computer interaction (HCI), and design fields. Through exploring the common discourse of phenomenological research in these three fields, this paper seeks to provide an introduction to a transdisciplinary foundation relevant to researchers working within the intersection of these fields. In my own design practice, this is explored through the co-creation of an intersubjective feedback cycle between designer and design recipient through a combination of co-design sessions and speculative design probes. Stopping short of suggesting a framework, this paper proposes that adopting a *phenomenological attitude* to research might benefit design researchers working in the medical field, providing a transdisciplinary common ground for working within, and communicating across; design, HCI, and medicine.

Keywords: phenomenology; medical device design; co-design; interaction

1. Introduction

Designing interactive medical products is a task that sits at the intersection of the fields of; medicine, human computer interaction (HCI) and design. In addition to this, this practice also intersects with the people who receive and use these objects of design. In an attempt to establish a foundation to work within, and across, these three fields; this paper seeks to identify and connect common contemporary discourses within these three fields. And in doing so identify a transdisciplinary foundation and an epistemological stance, an *attitude*, for researchers working on interactive medical devices.



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Within the medical discourse, contemporary medical research and clinical practice is increasingly embracing the idea that the historically rational, cognitivist discourse of the *medical model* does not, and cannot, provide us with all of the answers to medical problems (Svenaesus, 2014). This realisation has led to a new movement of *patient centred* medicine, and a greater patient participation within medical practice and research (Todres, Galvin, & Dahlberg, 2007). This patient centred movement can be seen as an attempt to augment and enrich the successes of the analytical, but impersonal, approach of traditional medicine. Pairing this approach, with a renewed focus on the patient's complex, subjective, experience with illness; and through this, achieving patient centeredness through an active inclusion of the patient experience within the medical discourse (Dahlberg, Todres, & Galvin, 2009).

Similarly the fields of Human Computer Interaction (HCI) and design have also acknowledged the limitations of their own, object focused, and rational cognitivist foundations (Dourish, 2004). Leading to a proliferation of user-focussed *design thinking* methods that attempt to situate an understanding of the user within the design process. This shift has occurred in addition to an increased interest in co-design and participatory design methods that actively include users, and their experiences, within the process of design (Bjögvinsson, Ehn, & Hillgren, 2012; E. B.-N. Sanders & Stappers, 2008).

Central to understanding this transition within these three fields is an understanding of the philosophical foundation of phenomenology that underpins them. A philosophical discourse that also shifts focus from objective rational cognition, to the subjective appearance of phenomena. Built primarily on the work of post 1930's philosophers, phenomenology is the study of the appearance of *phenomena* to consciousness (Merleau-Ponty & Smith, 1996). As a discourse, it is principally concerned with human experience and its embodiment within the world. In this way it contrasts with the scientific third-person approach, through focusing on an understanding of how *phenomena* are subjectively perceived in human consciousness, instead of an attempt to objectively understanding how they *are*. Striving not for scientific detachment, but rather embracing the richness and complexity of (inter)subjectivity (Finlay, 2012). This understanding is obtained with the goal of – and through the act of – richly articulating the complexity and fullness of subjective experiences (Todres et al., 2007).

Interest in the application of phenomenological thought to professional practice and research has grown, as many disciplines attempt to explore the subjective experiences of people within their research (Carel, 2011; Van Manen, 2001). This type of research is often undertaken by researchers with strong background in their own disciplines but less grounding in philosophy, focusing more on everyday experience (Van Manen, 2001). Dourish's concept of embodied interaction has built this application of everyday phenomenological inquiry into HCI research, placing the actions of embodied users at the centre of contemporary HCI research and practice (Dourish, 2004). Medical philosophy, through the work of Carel, Todres, Svenaesus, Thoomb's and others, has advocated for patient centred, phenomenologically informed thought within modern medical practice and research (Carel, 2011; Dahlberg et al., 2009; Svenaesus, 2014; Todres et al., 2007; Toomb's, 2013). Within design research, there is less of a strong discourse of phenomenological

research, but several authors have proposed the usefulness of its application to design research (Ho, Ma, & Lee, 2011; Hussain & Sanders, 2012); and many contemporary design methods share elements of the phenomenological *attitude*, even if not explicitly informed by, or articulated within, the wider phenomenological discourse.

This paper attempts to highlight, and connect, the discourses of phenomenological research within these three fields. It highlights the interactive medical device designer's position, at the intersection of these three fields, and through this establishes a transdisciplinary research foundation for work across them. This foundation is something that has been explored, in part through my own, ongoing, practice based PhD research; exploring the design of cochlear implant systems with Cochlear Ltd – a leading manufacturer of implantable hearing solutions. This design project explores how intersubjectivity can be achieved, and used, in design practice. Firstly, through a series of generative co-design sessions, augmented with a *phenomenological attitude*. The device use narratives established in these sessions were then extended into the creation of future narratives, through the exploration, and co-creation, of a series of speculative design probes (Dunne & Raby, 2013). Endeavouring, through design practice, to create an intersubjective feedback loop between designer and design recipient, and establish 'the user', and their experiences, as the transdisciplinary common ground within the project. In order to achieve this common ground, it was important to simultaneously, understanding the position of 'the user' within these intersecting disciplines.

Stopping short of suggesting a framework, this paper simply proposes to highlight the similarities in discourse within these fields, fields that are increasingly engaging with one another. This paper proposes that adopting a phenomenological '*attitude*' might benefit other design researchers working in the medical industry, and provide a transdisciplinary common ground for designers working in interdisciplinary projects across HCI and medicine; that is, designers working on interactive medical devices.

2. Healthcare; from objectivity to patient centred

The weaknesses of the traditional medical model have, over the last decade, become more apparent as the patient and their experiences are actively included, and more thoroughly considered in medical research and clinical practice (McWhinney, 2001; Todres et al., 2007). This approach of patient centeredness contrasts with the traditional *medical model* that views disease as having an objective existence of its own, separate from the patient. A model that has proven so successful at furthering medicine – and medical knowledge — that the weaknesses of its analytical and impersonal approach can seem insignificant when viewed against the strengths of its achievements (McWhinney, 2001). As such, modern patient centred medicine does not attempt to replace the successful system of scientific objectivity, but to enrich and augment it with an attempt to understand, and articulate, how illness is a function of the person as a whole (McWhinney, 2001). The patient centred method attempts to understand and acknowledge the complexity of "personhood, health and illness" (Todres et al., 2007) providing a "humanizing force" in healthcare (Dahlberg et

al., 2009) by acknowledging the subjective experience of patients. Within this approach, illness is seen as embodied within the person's world; this is in contrast to the Cartesian separation of mind and body, which sees the interest of the medical professional directed primarily at the 'body'. The patient centred approach additionally includes the patient's wider, experiential, "problems of living" (Toombs, 2013).

Even if not explicitly acknowledged, the patient will always be at the centre of healthcare practice as – like design practice – clinical medicine is necessarily at the intersection of the sciences and humanities. It is a scientific practice that has at its centre the embodied human being (Toombs, 2013). This devaluing of, or lack of explicit attention to, the experience of patients, has led those patients themselves to be the main drivers towards greater patient participation and awareness (McWhinney, 2001). Expressing their own subjective experiences through a 'remarkable increase' in the number books describing illness and patient experience (McWhinney, 2001; Van Manen, 2001), the rise of online, empowered patient (e-patient) communities, (Stanford Medicine X) and the increased involvement of patients in research design (Dahlberg et al., 2009). This could be seen as a reaction, by patients, against an oftentimes impersonal system. A system that can reduce patients' feeling of autonomy/ agency, instead treating them as passive recipients (consumers) of care. This, according to Todres, can also be seen as a symptom of a system increasingly abstracted into esoteric specializations and complex medical technologies, specializations and technologies that patients don't feel like they can understand (Todres et al., 2007). Through the act of expressing their experiences, patients have highlighted and exposed some of the limitations of the traditional, rational, medical system in addressing their experiential needs; and in turn have largely contributed to a drive toward more patient centred modes of care.

In my own field of research interest and practice, designing cochlear implant systems, much of the published research is undertaken with a scientific approach. An approach in which the recipient of the cochlear implant is seen, and measured, largely in terms of their hearing performance (Clark et al., 2012; Finlay & Molano-Fisher, 2008). This performance is largely objectively measured in standardized and controlled tests; an approach, as previously outlined, that often fails to recognise; not only differing 'real world' performance issues, but also the complex interplay between hearing performance and the recipient's wider experience and context. Thus, ignoring struggles that might arise in dealing with the complex life changes that come with implantation, but may not be directly related to clinically measurable outcomes (Finlay & Molano-Fisher, 2008).

The need for further focus on these experiential, quality of life outcomes has been called for by researchers within this specific field (Clark et al., 2012; Nardo, Anzivino, Giannantonio, Schinaia, & Paludetti, 2014; Stinson & Buckley, 2013) and by cochlear implant recipients themselves. Linda Finlay's phenomenological study with a cochlear implant recipient (Finlay & Molano-Fisher, 2008) suggests the potential of using the phenomenological research approach to illuminate the wider context of cochlear implantation. Through this, suggesting the benefits that a phenomenologically informed understanding could have to furthering

clinical care practices for cochlear implant recipients. I propose that the insights, and benefits, of phenomenological research in this field could also be applied to the research, development, and design of cochlear implant devices in collaboration with cochlear implant recipients through co-design practices. And that in turn, that this approach may be relevant to other designers with practice centred around the design of similar interactive medical devices.

3. Phenomenology; articulating first person experience.

The three movements towards a great focus on the richness and complexity of patient/user experience within the; medical, human computer interaction, and design fields, can all be viewed through an understanding of the descriptive philosophical method and practice of phenomenology. Built primarily on the work of philosophers Edmund Husserl, Martin Heidegger, and Maurice Merleau-Ponty; Phenomenology — from the Greek 'phainomenon' meaning 'appearance' — is the philosophical study of appearances rather than reality. As such, it is not a direct concern with the 'things of the world' directly, but rather how these things are experienced by our consciousness (Dourish, 2004).

Phenomenological research focuses on speaking, or letting speak, the things of our everyday world, as we encounter them, that is; see, feel, touch, hear and sense them (Van Manen, 2001). Through this articulation, the researcher attempts to understand not only the discrete, objective, sensory input, but rather the subjective context in which that input is perceived and interpreted. Understanding that every input is subjective and embedded within the culture, context, actions and relationships, that in turn gives it meaning. In practice, we experience not acoustic sensations or sounds of the phenomena, but the meaning as it is meaningful to us – for example, we hear the door shut.

For the phenomenological researcher to understand these subjective experiences, they must embrace understanding and articulating them within an awareness of these contexts and influences; embracing the complexity and unique nature of subjective experience. This explicitly first person approach contrasts with the rational scientific third-person approach, in that it is concerned with understanding how things, *phenomena*, are perceived in human consciousness. Rather than aiming to obtain only objective understanding of how they *are*. This approach aims to allay scientific detachment and embrace the richness and complexity of subjective experience (Finlay, 2012).

Recently, interest in phenomenology has grown in professional practice across a diverse range of disciplines outside of philosophy; from nursing, to pedagogy, to human ecology (Carel, 2011; Van Manen, 2001). Professional practitioners of phenomenological research focus on 'everyday concerns and practice', often using phenomenological research as a way to establish a shared transdisciplinary perspective — oriented to the realities of real-life/first-person experience — within the context of interdisciplinary professional practices and projects (Van Manen, 2001). This constitutes a useful philosophical framework through

which to view, understand, and take into account, the subjective experiences of people within research.

Qualitative methodologies are often difficult to explain objectively, the phenomenological method in particular is difficult to explain and is open to subjective interpretation by the researcher and participant. Rather than trying to articulate it as a traditional method, the philosopher Merleau-Ponty refers to it as something that "can be practiced and identified as a manner and style of thinking" (Merleau-Ponty & Smith, 1996; Van Manen, 2001). Referred to here as a *phenomenological attitude*. Within this attitude, the central concern is to focus on 'meanings' and subjectivity, with the aim of obtaining fresh, complex and rich descriptions of phenomenon. In this light, the *phenomenological attitude* is more of a way of being — an openness — on behalf of the researcher to 'see with fresh eyes' (Finlay, 2012). This attitude can be adopted and used in conjunction with any number of traditional formal or informal qualitative research methods (Van Manen, 2001) most commonly, the qualitative in-depth interview (Lopez & Willis, 2004). For practitioners working within phenomenological research it is the adoption of this attitude that is required.

The application of this form of phenomenological thought to medicine has contributed to both a more thorough understanding of a philosophy of illness (Carel, 2011), providing a guideline for understanding how to approach research and clinical care in a patient centred way, a way that acknowledges the complexity and subjectivity of individual experience (Dahlberg et al., 2009). Todres builds on this, calling for a model of 'life world' centred healthcare (Dahlberg et al., 2009; Todres et al., 2007) that addresses patients holistically, allowing them to live not as mere consumers of health, but rather as 'storied humans' who occasionally consult others for their specialist expertise. An 'existential partnership model' that acknowledges the differences in expertise, and understanding, between patient and professional without privileging one viewpoint over the other. The patient is regarded, at minimum, as an expert in their individual journey and context (Dahlberg et al., 2009). This approach draws obvious parallels to participatory design practice, which also includes individuals in the design process and does not privilege the 'expert' designer (E. B.-N. Sanders, 2002).

Carel similarly suggests that this way of thinking/ attitude could be applicable to many facets of medicine; from clinical care to research, from trial design to ways of measuring outcomes (Carel, 2011). I propose that this idea is equally applicable to researchers, engineers and designers working in the medical device design field. It can be applied not only as a way of understanding, and communicating, the wider impact of the disease or impairment on the patient's lives. But also, understanding the impact, or potential impacts, of the medical devices themselves on the patient's wider 'life-world'.

4. Human Computer Interaction (HCI); from cognition to user experience

The interest in adopting phenomenology as a philosophical research framework in professional practice has been also advocated in the HCI field. Dourish's concept of *embodied interactions* reflects the embodied perspective of phenomenological philosophy, placing the actions of embodied agents (users) at the centre of Human Computer Interaction research (Dourish, 2004). This focus on the experience of these embodied agents and their contexts is influencing contemporary HCI theory and practice in; user experience design (UX design) (Svanæs, 2013), social computing, and tangible interactions (Dourish, 2004). Similar to the medical field, this can be seen as a reaction to a discourse that was built on — and has similarly benefited from — a foundation of pre-1930's rational cognitivist discourse (Dourish, 2004). Like medicine and design practice, HCI also sits necessarily at the intersection of the sciences and humanities; it is a scientific, engineering practice, which has at its centre the actions and interactions of an *embodied* human being. This understanding has led to a new wave of HCI research and practice that embraces integrating usability with, fun, culture, and the total user experience (Svanæs, 2013). It embraces the idea of embodiment, provides a comprehensive understanding of the context of use and recognises the role of the body in interaction.

Dourish builds on Heidegger's idea of embodiment, taking it to be central to the designed phenomenon (Dourish, 2004). Heidegger separates tools that we use into two categories, the *ready-at-hand* and the *present-at-hand* — depending on their embodiment at particular points in time. Dourish explains this through an interaction design example: when using a mouse to control a computer we primarily act *through* the mouse. It becomes an extension of our hand, a tool through which we accomplish a task. In this way the mouse as an object/technology disappears from our immediate consciousness as we are caught up in performing our onscreen intention. The mouse — as object — fades into the background, becoming part of our sense of self, embodied, ready-at-hand. When this seamless interaction is broken — such as when the mouse hits another object — our consciousness is directed to the *object* of the mouse. When we are reminded of the mouse as an object, it loses its embodiment, it becomes present-at-hand. When performing a task we focus our intentionality on that task, when our tools can't be embodied, we must consider them consciously, separate from our task, undesirably redirecting our intentionality away from the task (Dourish, 2004).

This notion of embodied interaction is particularly interesting to consider in regard to interactive medical devices such as cochlear implants. As a device that is continuously in use throughout the day, the cochlear implant system — and indeed most medical prosthesis — ideally exist in a state of *readiness-to-hand*. Transparent to us in use, getting out of the way of us accomplishing of the daily tasks of our intention. It is only when devices stop working seamlessly, or when we consciously choose to reflect on them, that they emerge from the background as an object (Dourish, 2004). As such, I propose that we need to approach the design of interactive medical prosthesis with an understanding of how these objects become

embodied. Drawing upon the work of Dourish, and phenomenological philosophers, to understand this notion. In addition to developing a rich intersubjective understanding of the users of our designs through the involvement of these users within the design process. An understanding that is explicitly centred on the patients, their experiences, and their wider 'life-worlds'.

5. Applying the phenomenological *attitude* to industrial design research

In parallel with the medical and human computer interaction fields, industrial/ product design has similarly felt the strain of its rational cognitivist discourse, leading to a proliferation of newer user oriented design thinking frameworks and methods (E. B.-N. Sanders, 2002).

Within the object-oriented paradigm of design, the perception of the product can be seen as entirely dependent on the physical properties of the product and their objective perception. This idea of objects having objective qualities implies that there is a correct, singular interpretation of the product, and thus that a designer can control how the user experiences this product through the design of these objective properties (Hussain & Sanders, 2012). In many cases this has proven to be untrue, with users interpreting and using products in ways that the designers could never have imagined. Instead, in co-design and participatory design frameworks the user is empowered and given greater agency within the design process (Ho et al., 2011). The user's perspective is also better addressed through the designer themselves being aware of — and designing for — the variety of interpretations and uses of their products. This awareness of subjectivity can be achieved through adopting a *phenomenological attitude*.

Hummels and Overbeeke describe the earlier state of design as 'lost in abstraction and procedure' in calling for designers to embrace a phenomenological stance that values the 'primacy of experience' and intuition over abstraction (Hummels & Overbeeke, 2010). This call for a privileging of the experience of users echoes the movements in the medical and human computer interaction fields discussed above. The application of this phenomenological stance, or *attitude*, has been explored by several other design researchers and practitioners (Ho et al., 2011; Hummels & Overbeeke, 2010; Hussain & Sanders, 2012). In addition to this explicit research, many other practitioners and researchers are exploring approaches such as co-design and participatory design that are phenomenological in feel or *attitude* even if this foundation is not explicitly stated, acknowledged, or drawn upon (L. Sanders & Stappers, 2012). These methodologies privilege the primacy of the subjective first person experience and do not see the designer as the exclusive expert. Hence, they can be usefully augmented with an explicit understanding of the *phenomenological attitude* discussed above, and thus used within a phenomenological research design (Van Manen, 2001).

6. Phenomenological design in practice; a brief overview

Earlier, I referred to Todres' call for a greater philosophical discourse around patient led/informed care as a strategy to avoid the consumerisation of health (Todres et al., 2007). In a similar vein, greater philosophical depth around user centred design methodology could help designers avoid the pitfalls of focussing on users as potential consumers only. Or as 'passive information providers' in a paradigm that sees designers as the sole expert creator (Ho et al., 2011). Similar to Todres call for a life-world led care framework to extend and replace current patient-led care, I propose that a life-world led framework could be a relevant extension of user-centered design frameworks; *life-world led design*. And would align designers working in this field with researchers exploring life-world led healthcare.

Similar to Todres life-world led care; an authentically person centred design approach would include a similar focus on; the philosophy of the person, their wellbeing, and their values beyond their problems. And would also require a design philosophy consistent with this. The goal here is not just empathy, or to 'see through their eyes', instead, Hussain and Sanders suggest that the goal is to work together to reach a shared understanding or 'fusion of horizons' (Hussain & Sanders, 2012). Ho et al also express the danger of the identity of the real user being caricatured into a fragmented 'user', an abstract user that is 'removed from the experiences that disclosed it'. An abstract, conceptual 'user', inspired by, but irrelevant, to the particular users involved in the design research (Ho et al., 2011). Adopting the *attitude* of the phenomenological researcher enables us to instead embrace the rich, complex, understanding that phenomenological research strives for.

These cautions suggest that good phenomenological design research — or good design research in general — should embrace the idea of obtaining, and articulating, a rich and complex view of the user and their life-world. Further, by working together with users to obtain this view, and integrating them fully within the design process, users can be empowered to contribute to the construction of not only the designed object; but its underlying narrative of use, and nuanced subjective relationship to its context of use. My ongoing, project-grounded research, in collaboration with Cochlear Ltd explores improving the usability of cochlear implant systems. Due to the nature of the interactivity of the products involved, this project sits at the intersection of the three disciplines explored above; medicine, human computer interaction, and design. Through this exploration I have attempted to develop a research design consistent with the *phenomenological attitude* – or phenomenological discourse – discussed in this paper. To date, this in-progress research has focused on co-creating narratives with cochlear implant recipients, around the future and present of cochlear implant devices. The project has been structured in three main sections: first, a series of generative co-design workshops (L. Sanders & Stappers, 2012), qualitative interviews, and cultural probe activities (Gaver, Dunne, & Pacenti, 1999) between designer and recipients of cochlear implants. Secondly, designer-developed insights from these sessions were translated into a series of rapid prototyped, speculative design probes (both working (experiential) and non-functional (conceptual) prototypes (Dunne & Raby, 2013). Thirdly, a further round of co-design sessions with implant recipients to; interrogate the

speculative design probes, co-create narratives around device use and allow cochlear implant recipients to participate in the developing, adapting and changing these devices and use narratives to suit their unique life-worlds. These activities will then be repeated, creating a cycle of intersubjective narrative construction between designer and design recipient. This reflective process has been designed to facilitate a shared understanding of phenomena, context and usability between designer (who can only vicariously understand the life-world of the recipient) and end-user.

This model of design research practice echoes the model of life-world lead care referred to in the medical field (Dahlberg et al., 2009; Todres et al., 2007) in that it sees device recipients as 'storied humans' in need of assistance of specialist expertise, but not subservient to it. This is an 'existential partnership model' that acknowledges the differences in expertise – that is, acknowledging that the recipient/user is, at minimum, an expert in their own experience – and does not privilege one view point over the other. Instead, it works to achieve a blending of the two, mediating between the technical expertise of the designer (and their understanding of the project's technical realities) and the experiential desires and needs of the recipient. In this way, the process co-creates a device design narrative with – not for – the people who will then use these interactive medical devices.

7. Conclusion

This paper has attempted to contextualize my own ongoing research in the design of interactive medical devices, placing it within the larger fields of; medical research, human computer interaction, and practice-based design research. The concurrent exploration of these fields has identified a common transdisciplinary discourse in the philosophical framework — and practice — of phenomenology. This paper proposes that an understanding and application of phenomenology in design research can enrich practice through incorporating and articulating a rich and complex understanding of the patient/user experience. Arguing that this can be achieved through; adopting the open *attitude* of the phenomenological researcher, focussing on the first person subjective experiences of patients/users, and empowering patients/users to participate within the design and research process. By designing in this way, it is proposed that the designer can play a greater role in establishing a transdisciplinary common ground for projects that span design, HCI and medicine and establish an intersubjective understanding between designers and the recipients of their designs through design practice.

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