

## Using Phenomenological Hermeneutics to Gain Understanding of Stakeholders in Healthcare Contexts

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The use of medical products differs from so-called everyday products in that people need them, rather than have a special desire to use them, and also because the use contexts often relate to care. For human-centered designers, it is essential to understand stakeholders as well as use contexts, and more research is needed about how products and services can facilitate improved healthcare experiences. In this article, an understanding of stakeholders and use contexts in the case of children's medical treatment is attempted through a phenomenological hermeneutics approach inspired by the views of Heidegger, Gadamer, and van Manen. We chose this approach because it encourages gaining an understanding of care as a phenomenon through an interpretative dialogue. Based on an analysis of interviews conducted with nurses and parents who have experienced medical treatment of children aged 0 to 3 years, we present five themes capturing the perspectives of the phenomenon of care in the case of children's medical treatment. Another outcome of this analysis is an appraisal of phenomenological hermeneutics as a human-centered design approach and its utilization for the design of medical products. We argue that its strength lies in the dedication toward lived experience, responding to a human-centered view that acknowledges human agency, competence, and participation.

Keywords - Healthcare, Human-Centered Design, Phenomenological Hermeneutics, Phenomenon of Care.

*Relevance to Design Practice* – This article explores how phenomenological hermeneutics fits within human-centered design and suggests that it is valuable for informing and inspiring designers addressing lived experiences of stakeholders in healthcare contexts.

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## Introduction

Human-centered design represents an overall perspective wherein human needs and concerns are the foremost drivers for the development of technologies. As such, human-centered design research deals with people who use or who are potential users of products and services, and it aims to provide frameworks that can contribute to more successful solutions (Roth, 1999). Human-centered design applied to healthcare contexts is important for at least two reasons. First, medical products and services that fail to respond to the needs of the stakeholders can, at worst, have disastrous consequences. As such, the healthcare context imposes on designers a special responsibility to ensure that products and services are well adapted to a wide variety of stakeholders, such as patients and healthcare personnel. Second, medical products are typically used and purchased because people need them, rather than because they have a special desire to use them. Since users do not have a choice in using these products, it is important for designers to be sensitive to stakeholders and use context. In this paper we suggest that such sensitivity can be accomplished through seeking gained understanding of stakeholders and use contexts by using phenomenological hermeneutics.

In this article, the term 'stakeholder' is employed for individuals and groups who have a direct interest in the product or service, the situation and its development (Eason, 1998). There is a need for more knowledge on how designers can gain an understanding of stakeholders' experiences with products that they are compelled to use for medical reasons. Despite the desire to pay special attention to people, the application of human-centered design principles in healthcare contexts can be challenging for a number of reasons. Health-related issues are often vulnerable. For this reason, it can be difficult not only to actually come in contact with people and involve them in studies but also to relate to people's experiences, which can be demanding. As such, healthcare contexts often challenge designers because people and their situations can appear hard to reach and relate to.

Although phenomenological hermeneutics has at its core an acknowledgement of a human-centered view based on lived experience, it has received limited attention in design literature. This article is an attempt to understand how humancentered designers can benefit from taking a phenomenological hermeneutics perspective for meeting the needs of stakeholders in healthcare contexts. We are not drawing an explicit distinction

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between the notions of hermeneutic phenomenology and phenomenological hermeneutics. As Paul Ricoeur (1975) emphasized in 'Phenomenology and Hermeneutics':

The question is no longer to define hermeneutics as an inquiry into psychological intentions which are hidden in the text, but as the explication of the being-in the-world shown by the text. (p. 93)

An analytic distinction can be made in that phenomenological hermeneutics is sometimes used to describe a method aiming at a certain phenomenon (Lindseth & Norberg, 2004), while a characteristic of hermeneutic phenomenology is to present a rich and deep account of the phenomenon by simultaneously acknowledging one's own implicit assumptions about it as well as one's attempt to make them explicit (Cohen, 2001). One reason to choose phenomenological hermeneutics for this article is that to be hermeneutic means to be aware of one's own perceptions and experiences in a subjective, cultural, and historical context (this is referred to as the lifeworld) and include them in the interpretation process. Thus, in the ductus of phenomenological hermeneutics, the main question of this article is not "How should we analyze care?" Rather, it is one of the following: How do the stakeholders experience care in the hospital situation? What is the core of their experience? What can I, as a designer, learn from them, and how? The results of such research is then to elucidate what a particular caring experience means for parents and nurses in order to learn more about how to design sensible products for children's medical treatment.

The research is connected to a one-year pilot project called BLOPP conducted in 2012. BLOPP is a Norwegian acronym for "Barns Legemiddelopplevelser," translated as "Children's pharmaceutical experiences". In this article, care related to the medical treatment of children aged 0 to 3 years is explored (i.e., Infants and toddlers, here referred to as young children). More specifically, we examine the phenomenon of care related to caregivers' (parents' and nurses') experiences in the case of

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young children's nebulizer treatment. Nebulizer treatment is used for treating respiratory diseases. While a lot of design research addresses children, very little deals with the context of young children's medical treatment and possible implications for medical product design (Allsop & Holt, 2013). The purpose of this article is two-fold: 1) to gain an understanding of how caregivers experience children's nebulizer treatment in terms of care and 2) to provide an appraisal of phenomenological hermeneutics as a human-centered design approach.

The article is structured as follows. First, we present some key aspects of phenomenological hermeneutics and we reflect on how it can inform and inspire human-centered design in a different way than other existing human-centered approaches, i.e., its position as a methodological supplement. Moreover, we argue that exploring the phenomenon of care is crucial for understanding the context in which medical products are being used. Understanding the context is crucial because products do not exist in a vacuum, rather their assigned meaning depends on how, why and when people use them, i.e., the circumstances under which they are being used by people (Leong & Clark, 2003). Next, we discuss a case dealing with nebulizer treatment of hospitalized children with respiratory diseases. Phenomenological hermeneutics is introduced for interpreting interviews conducted with parents and nurses in terms of care, and five themes that capture the notion of care are presented. Conclusively, we reflect on phenomenological hermeneutics as a human-centered design approach, and we present a prototype as an example of its utilization in our specific case.

## **Phenomenological Hermeneutics**

#### **Key Issues in Phenomenological Hermeneutics**

Our motivation for exploring how phenomenological hermeneutics fits under the human-centered design umbrella resides, among others, in the notion by Donald Schön (2005) that "problem setting" is a necessary condition for "problem solving" (p. 40). Design thinkers follow Schön's argument when, for example, emphasizing that methods and tools should support designers to be "prepared-for-action" rather than "guided-in-action" (Stolterman, 2008, p. 61). Phenomenological hermeneutics can be a useful approach, for example, by supporting designers in their early navigations. Exploration of a phenomenon through an interpretative dialogue can further inspire to acknowledge complexity, rather than hastily steering away from it. Thereby, designers can attend a rich solution space, reflecting openly about multiple realities.

Phenomenological hermeneutics stems from ideas that Martin Heidegger presented in his fundamental work 'Being and Time' in 1927 (Embree, 1997). These ideas were, among others, adapted by Hans-Georg Gadamer in 'Truth and Method' which was first published in 1960. In that the intention was not to provide a "method of interpretation" fitting into the scheme of modern human sciences, but rather a reflection on what happens "over and above" our understanding (2004, p. xxvi). According to

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Gadamer, the Enlightenment's ideal of overcoming all prejudices by rationality proved itself to be a prejudice. He developed a method-"the hermeneutic circle"-in which the meaning of any text (e.g., product, artifact) relates to the historical situations of both the author and the artifact. The hermeneutic circle refers methodologically to the idea that a person's understanding of a text or an artifact as a whole is established by referring to their [own] history and cultural background. The person and the text are referring to each other in a way that cannot be excluded from the other. The interpretation of an artifact has to be explored within its cultural, historical, and in situ context, as well. Through phenomenological hermeneutics, the researcher aims to "disclose truths about the essential meaning of being in the life world" (Lindseth & Norberg, 2004, p. 151). A key method is to go beyond the data and look for hidden meaning, rather than assuming that data will "speak" for themselves (Maggs-Rapport, 2001).

Phenomenological hermeneutics attempts to grasp lived experience in a comprehensive way. In this perspective, the main challenge for design is to find a balance between the sphere of technology and the sphere of non-instrumental human needs, i.e., between levels of reality that can be directly manipulated and those that resist such manipulation. Doing research from a phenomenological perspective is about questioning the way we experience the world and desiring to know the world in which we live as human beings (van Manen, 1990). A central argument in phenomenology, referred to as the principle of intentionality, is that knowing the world is inseparable from being in the world. From this point of view, research can be understood as a caring act, as van Manen points out: "We can only understand something or someone for whom we care" (p. 6). A generalizable ideal of natural science research is that actions should be repeatable and subjects replaceable. In opposition to that, phenomenology draws attention to the unique and irreplaceable:

In phenomenological research the emphasis is always on the meaning of lived experience. The point of phenomenological research is to 'borrow' other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole human experience. (p. 62)

Heidegger's (2010) 'Being and Time' is an investigation about the meaning of being (Sein). The human being is called Dasein (Being-there). The hermeneutics of Dasein signify an individual, which is fundamentally concerned about its own way of being. That means that it is (to a certain degree) conscious of its body and mind, thinks about its existence and has the intention to exist in a certain way. Because Dasein is so engaged in contemplating and transforming its existence, the main feature of Dasein is called "care" (Sorge). This means taking care for oneself, other beings, nature and things. "The essence of Dasein lies in its existence. The characteristics to be found in this being are thus not objectively present "attributes" of an objectively present being which has such and such an "outward appearance" but rather possible ways for it to be and only this (p. 69). Existence is determined by Dasein via the possibilities the individual chooses. The genuine constitution of Dasein is "being-in-the-world" which means that individuals are engaged in the world through dwelling, not opposed to it as objective observers of various phenomena. Being-in-the-world, as familiarity with the world, is the first existential mode of Dasein, expressed by its dealing with those beings which Heidegger calls "equipment": devices for writing, sewing, working, transportation, measurement etc. Thereby, the respective equipment stands in a co-constitutive, reversible and dynamic context with its use and the situation.

We shall call the useful things kind of being in which it reveals itself by itself handiness. It is only because useful things have this being-in-themselves, and do not merely occur, that they are handy in the broadest sense and are at our disposal... Here the world is encountered in which wearers and users live, a world which is at the same time our world (p. 66)

One of Heidegger's main intentions in 'Being and Time' is to argue against the idea of an objective reality defined by mathematics and natural sciences. From his point of view this idea does not answer questions such as how to understand Dasein, life, humans, artworks, language etc. On the contrary, if the existence of an objective reality is assumed, the factual life-world, in which those questions arise, has to be denied, because it cannot be described in terms of an objective reality. While the life-world is filled with meanings and values, these characteristics are non-existent in the reality descriptions of the natural sciences.

In 'Being and Time' Heidegger tries to show that the assumed superiority of an objective reality over a reality of daily life practice is a misapprehension, based on a concealed philosophical prejudice. To summarize: the concrete world is not a world of things but a world of equipment—a world of the ready-to-hand (Zuhandenes). The equipment as the ready-to-hand is not a thing or an object which gets additional qualities, but the structure of usefulness in a certain context is the being of the equipment. In its thingly character it is the present-at-hand (Vorhandenes). The present-at-hand is just visible if a breakdown occurs: if something is destroyed, stands in the way or is not usable any more. Heidegger says that in these situations the mere present-at-hand character of the ready-to-hand appears.

Heidegger's argumentation shows that the experience of a meaningful world is the condition for the discovery of things as objects. The possibility of (scientific) knowledge of an objective reality is based on the world and the experiences of Dasein, whose existence is not objectively real, even if it incorporates the possibility of the objectivating recognition of beings.

The being-in-the-world of Dasein has a possibility of being in the recognition of an objective reality, however, in a way, that the being of Dasein, its reality and its world is inevitably prior to this objective reality. And this implicates at the same time that the being of language, art, law and the discursive actions of humans cannot be understood from the position of an objective reality in the meaning of the natural sciences. According to Heidegger, human existence is being-in-the-world (Lindseth & Norberg, 2004). This world, also denoted the lifeworld in Husserl's work, is the world as it shows itself to our consciousness and is different from the objective, outer world.

Following Heidegger's existential philosophical ideas, van Manen (1990) suggested four lifeworld existentials as guides for reflection in the research process. In this article, we use these lifeworld existentials for the analysis of care. They are the lived body (corporeality), lived human relation (relationality), lived space (spatiality), and lived time (temporality):

They all form an intricate unity which we call the lifeworld—our lived world. But in a research study we can temporarily study the existentials in their differentiated aspects, while realizing that one existential always calls forth the other aspects. (p. 105)

The existential of lived body relates to the phenomenological consideration about how "we are always bodily in the world" (van Manen, 1990, p. 103). The existential of lived human relation refers to the relations that we maintain with others—how human beings are social beings making meaning through sharing experiences. The existential of lived space can be understood as "the world or landscape in which human beings move and find themselves at home" (p. 102). Furthermore, van Manen understood lived space as felt space. The existential of lived time refers to subjective time, rather than clock time—for example, how we feel that time appears to pass quickly when we are having a good time.

In this article, we understand lived space to include the physical environment and the things/objects that surround us. The hospital environment with all of its medical products, such as the nebulizer device, is of particular interest in this article. We draw on the semantic argument in design that people do not see and act on the physical qualities of products but rather on what they mean to them (Krippendorff, 2006). From this perspective, thus, the idea of lived space as felt space is relevant. Objects and products contribute to meaning-making in people's daily lifeworld (Battarbee, 2004; Fredriksen, 2011; Krippendorff, 2004).

To summarize, from a methodological perspective phenomenological hermeneutics asks for taking a deliberate choice for treating data in relation to interpreting a situation. Several authors claimed that incoherence in human-centered design rests on uncritical adaptation of methods of contradicting research paradigms or worldviews (Dourish, 2006; Gaver, Boucher, Pennington, & Walker, 2004). If a "positivist" method and the designer's ambitions and knowledge do not match, a methodological gap appears (Lee, 2012). Phenomenological hermeneutics differs from other human-centered approaches that focus mostly on applying methods and less on the interpretation of the resulting data. Since the main concern of phenomenological hermeneutics is exploring the ways in which people experience their lifeworld, this approach has a normative implication as well. Besides providing an alternative to quantifiable and clear-cut user data it can contribute to develop empathy and role-taking for the study participants and train designers to learn to listen (to themselves as well as to the study participants).

From a designerly perspective, phenomenological hermeneutics informs and inspires human-centered design in a direction that takes the complexity of human experience and meaning-making regarding specific phenomena into account. In this way, it can be valuable for designers to develop a solid (methodologically coherent) basis for "problem setting", identifying and developing a wide range of design proposals and proposing more holistic solutions.

#### The Phenomenon of Care and Healthcare Design

Care is a central aspect of human interaction during medical treatment. As such, the phenomenon of care should be of particular interest for human-centered designers working within healthcare. Recently, there is an increased focus on experience-based design in healthcare. A pleasurable experience with medical equipment is considered to be a critical component in users' adherence to medical treatment (Gloyd, 2003). Moreover, patient-experience design has been pointed out as a new paradigm for the development of medical products and systems aimed at improving patient adherence (Turieo, 2012). Mullaney et al. (2012) used "quick" ethnographic methods to explore patient experience within cancer treatment and concluded that human-centered design thinking is "ideal for finding new ways to generate the frame-shift required to think beyond the 'cure' to person-centered care and wellbeing" (p. 37). However, genuine application of design practice and design research in the domain of healthcare is still largely unexplored (Bate & Robert, 2007).

We argue that care is one key phenomenon for design practitioners and researchers to attend to when seeking to understand and influence people's healthcare experiences. The term "care" has a twofold meaning, referring to love and attentiveness as well as concern and grief (van Manen, 1990). Care can further be considered a human life fundament because people have a general desire to be cared for (Noddings, 2002). Care is also a relational phenomenon. Noddings (2013) understood a caring relation to consist of one who cares (the "one-caring") and the one who is cared for (the "cared-for"). The one-caring engages in caring by sharing a feeling, a notion that Noddings (2013) referred to as engrossment. Rather than acting in a rule-bound manner, the one-caring acts out of desire for promoting the wellbeing of the cared-for. The one-caring and the cared-for are both active and contributing participants in their caring relation, and in this way, they depend on each other for establishing a caring encounter.

# The Phenomenon of Care in the Case of Children's Nebulizer Treatment

#### The Case of Children's Nebulizer Treatment

Respiratory infections lead to frequent hospitalization of infants and toddlers worldwide. Respiratory syncytial virus (RSV) commonly causes respiratory infections, and in the United States, for example, more than 100,000 children with RSV are hospitalized each year (Krilov, 2011). Nebulizers are used for treating respiratory diseases. Figure 1, obtained from our observational studies, gives an impression of how nebulizer treatment is administered. To receive the medication, the child wears a face mask covering the mouth and nose and inhales the medication through passive breathing for between 5 and 10 minutes. The treatment is typically repeated every 2-4 hours, often over several days.



Figure 1. Nebulizer treatment. Photo: Marikken Høiseth.

The motivation for addressing the case of children's nebulizer treatment is that the treatment itself comes with many challenges. The overarching challenge is that many children resist nebulizer treatment, and it is suggested that approximately 30% of young children are distressed during the treatment (Esposito-Festen et al., 2006). Distress expressed through struggling, crying, screaming, and turning away from the mask reduces the amount of medication reaching the lungs (Amirav, Balanov, Gorenberg, Groshar, & Luder, 2003; Iqbal, Ritson, Prince, Denyer, & Everard, 2004). Different forms of distress and lack of cooperation lead to tense interactions between children and their caregivers. It is not unusual for physical coercion to occur, and sometimes, nurses decide to terminate the treatment. Healthcare experiences that are perceived as scary, painful, or uncomfortable deserve designers' full attention.

#### **Background of the Research**

The aim of the BLOPP project was to explore how design and technology can motivate children with respiratory diseases to take prescribed medication and promote positive interactions between children and caregivers, thereby increasing adherence to medical treatment. The project group was multidisciplinary and consisted of people with backgrounds from industrial design, pharmacy, and human-computer interaction. Between January and March 2012, members of the BLOPP team conducted participatory observations of hospitalized children who received nebulizer treatment and carried out semi-structured interviews with their parents and the health personnel who administered the medication. The purpose was to gain a better understanding of how children, nurses, and parents experience nebulizer treatment. The fieldwork was approved by The Regional Committee for Medical and Health Research Ethics of Central Norway and head physicians at the children's ward.

#### **Research Process**

Our research process aimed at gaining an understanding of care as a phenomenon through an interpretative dialogue—that is, a phenomenological hermeneutics approach. Analyzing the phenomenon of care, we specifically draw on interviews conducted with nurses and parents who have experienced nebulizer treatment of young children.

Both participatory observations and interviews were carried out to get a good impression of what the treatment entailed for the children and their caregivers. Results from the observational part of the field study are reported in (Høiseth, Keitsch, & Hopperstad, 2014; Høiseth & Hopperstad, 2015). Even if this article focuses on the interviews, the authors' insights include and must be seen in relation to previous analysis of the observed treatments. An initial intention was to include the child patients as active participants in the research. This, however, proved to be difficult because the majority of the children seemed too young and in addition it did not seem appropriate given the children's health conditions. Even so, the observations were vital for understanding how nebulizer treatment is conducted and how the participants interact with each other and the connected products.

Following the participatory observations of the nebulizer treatment of nine children between the ages of 4 months and 2.5 years, the first author interviewed nine parents and six nurses. One nurse was interviewed three times, and one nurse participated in two treatments but was only interviewed once. In total, this resulted in 17 interviews. The interviews took place in the hospital rooms, in a quiet part of the corridor, or in the nurses' break room. The interviews were audio-recorded and later transcribed verbatim. All participants were informed about the purpose of the research and gave written consent. Given that caregivers are understood to be stakeholders.

The purpose of a semi-structured interview is to obtain people's descriptions of their lifeworld and to interpret the meaning of the described phenomena (Kvale & Brinkmann, 2009). Such interviews come close to an everyday conversation, but they differ because the researcher has a professional intention and asks an open question about predefined themes. The role of the researcher is to ask a series of structured open questions and to probe more deeply into respondents' beliefs, attitudes, and inner experiences by following up their answers (Gall, Gall, & Borg, 2003).

The parents were interviewed to gain an understanding of how they experienced different aspects related to their hospitalized children's nebulizer treatment. The interviews with the nurses were conducted to construct knowledge about how they experienced administering nebulizer treatment to young children by asking questions about the specific event that had been observed as well as general events. The questions were formulated based on these intentions. The interview guides for the parents and the nurses covered the same following topics: their own experiences of participating in pediatric nebulizer treatment (e.g., how do you experience the current nebulizer treatment?), their perception of the children's experiences related to the treatment (e.g., how do you perceive your child's experience of the treatment situation?), their understanding of the social interactions that take place during treatment (e.g., how would you describe the interaction between the child and yourself in the treatment situation?), and suggestions for improved treatment (e.g., which suggestions do you have for improving the nebulizer device?). Gained understanding through treating predefined questions, repeating questions, slightly reformulating questions and further probing, characterized the actual interviews and can also be understood to reflect the phenomenological hermeneutics approach at large. The interviews lasted between 20 and 40 minutes.

From a phenomenological perspective it is also important to reflect on the different roles that parents and nurses have within the children's lifeworld. Parenting and nursing care differ as social action in the everyday world. Intersubjective relations between actors and the child can e.g., be analyzed related to the social phenomenology of Schütz that is guided by intersubjective dimension and relationships between different stakeholders (de Jesus et al., 2013). Due to time and topic limitations this was not done in this article but it is seen as an important follow-up for further research.

Our approach for interpreting the interview texts—that is, the verbatim transcripts of 17 interviews—was to move between the following three steps: naïve reading, thematic structural analysis, and comprehensive understanding. These steps form the phenomenological hermeneutics approach of Lindseth and Norberg (2004).

First, the first author read the interview texts several times. The purpose of this step—that is, naïve reading—was to grasp the meaning of each single text as a whole (Lindseth & Norberg, 2004). While transcribing and afterward reading each interview, the first author's feelings from the interview setting were recreated. She recalled the atmosphere during each interview and could, as such, revive how the interaction with the other person unfolded—how experiences were conveyed and shared through words, moments of silence, gazes, gestures, and sounds. Through a reflective dialogue with the text, the first author got an impression of what caring "is about" in the specific case (Storli, Lindseth, & Asplund, 2008). When the authors discussed together, another reflective dialogue was initiated, which gradually led to an integrated impression.

There are different ways to conduct a thematic structural analysis. At a general level, we have followed the idea that creating a thematic understanding in human science research should be seen as a free act of "seeing" and interpreting meaning, as opposed to a clear-cut and mechanical application of counting acts or terms as they appear in, for example, a transcript (van Manen, 1990). Our approach was to construct themes by dividing the texts into meaning units (Lindseth & Norberg, 2004). For each single interview text, we identified and clustered meaning units. A meaning unit is part of a text, ranging from just a few words to several paragraphs, which conveys one essential meaning that is relevant for illuminating the phenomenon. Next, we combined the interview texts into two groups-the parents and the nurses. The reason for separating the parents and the nurses was that they have different roles in the medical treatment. Then, all of the meaning units within each of the two groups were further clustered. Based on the total collection of the clustered meaning units, the first author suggested a preliminary set of themes to represent the clusters.

A comprehensive understanding was gained by, as it were, focusing again on care as an overarching phenomenon. Through discussions, the two authors collectively refined the themes further and used the lifeworld existentials as reflection guides. We reflected on how the themes conveyed different, albeit connected, meanings of care. The themes were considered in relation to our impressions of each single interview text as well as relevant literature and theoretical perspectives (Lindseth & Norberg, 2004). Moreover, we reflected on own pre-understanding and how the themes broadened our awareness in terms of challenging our first notions of "the problem." This also included a discussion of how designers could make use of the themes to increase understanding of stakeholders and use contexts.

Our interpretative process, consisting of the three described steps, reflects a circular movement between the "whole" (care as a phenomenon) and the "parts" (perspectives on care as a phenomenon). Such movement between the "whole" and the "parts" proceeded in a more fluent manner, rather than as strictly organized shifts. The authors entered the hermeneutical circle with their own pre-understandings. Even though prior understanding is difficult to account for, as it is embedded in one's life, we can reflect on our motivations for conducting this study-that is, our professional pre-understanding. With a background in industrial design, the first author arrived with the view that designers have a special responsibility when it comes to adapting products that take part in medical treatment and healthcare contexts to the users. The second author has a background in philosophy, and her research revolves around welfare and design. Our intentions, assumptions, experiences, and backgrounds have contributed to the interpretative process. However, the interpretative process does not stop here. In line with phenomenological hermeneutic thinking, this article can be seen as an invitation for other people who represent different fields to continue the work of analyzing and interpreting the themes that are presented in the following.

# Findings: Five Themes Capturing the Phenomenon of Care

Based on the interviews, we constructed five themes that capture perspectives of the phenomenon of care in the case of children's nebulizer treatment. We understand a theme to be a means to get at the notion by giving it shape and content while acknowledging it as a reduction that cannot completely unlock the deep meaning (van Manen, 1990). Each theme can be understood to represent a sub-phenomenon of care. Taken together, they give shape to the phenomenon of care in the case of children's nebulizer treatment. While the two first themes reflect the meaning of care as experienced by parents, the other three themes regard parents as well as nurses.

#### Theme 1: Feeling Helpless

The parents in this study frequently referred to feeling helpless. The kind of helplessness that parents experience before attending the hospital can be severe:

When we were at home and he was at his worst I felt pretty small and terrified actually... because I didn't know what to do. ... When feeling he almost doesn't breathe in the evenings ... it becomes a bit like ... almost a bit like hysteria. ... You get stressed throughout. (Diane, mother)

Other parents experienced helplessness at the hospital in realizing that there is little or "nothing you can do":

You are helpless and powerless. ...Quite simply ... there is nothing you can do for your child. ... This actually concerns the airways ... your child has problems breathing ... and you can't do anything ... just be present. ... It is kind of a sore feeling. (Hannah, mother)

Yes, it is difficult because you know there is nothing you can do ... besides comforting and being there. (Andrew, father)

Helpless ... is what I am. ... I can only stand there and watch. (Christina, mother)

Some parents expressed a kind of helplessness related to being confined to an isolated space:

We are at an isolate here, too. ... You are supposed to be in the room and as little as possible out in the corridors and stuff. (Kate, mother)

You get lots of emotions. ... You can get upset and everything, but I think it is very smart and easier to wait until you get out of this tiny little room. (Hannah, mother)

Experiencing helplessness relates to the meaning of care as a bodily phenomenon. Taking part in a caring relationship by feeling helpless is experienced as "nasty," "sore," "feeling small," "terrified," and "stressed throughout." As such, helplessness is manifested as bodily experiences. Parents, too, feel their children's diseases through bodily expressions. "Feeling small" also relates to care as a spatial phenomenon—the felt space. Moreover, the hospital room, which is a physical isolate in attempts to hinder the spread of infection, contributes to the feeling of helplessness. The physical isolation can be understood to reinforce the limits one has as a caregiver.

Further, experiencing helplessness relates to the meaning of care as a relational phenomenon. Here, parents' helplessness refers to an inability to directly influence the child's wellbeing through their own actions. As such, helplessness appears to challenge the role of the parents: "you know there is nothing you can do." Whereas the role as one-caring in everyday life can imply both the ability and the responsibility to repair and sort out, caring for a child who is unexpectedly seriously ill can mean a readjustment of one's perceived role in the caring relationship. Helplessness, then, reflects a tension in a parental desire to provide care, resulting in a medically healthy child and the realizations of one's own limitations.

#### Theme 2: Feeling Cared-for

Several parents were explicit about that they, too, felt cared for:

I feel that we are incredibly well cared for so that I can relax, and it is very clear that the ones treating her know what they are doing. (Kate, mother)

Here at the hospital, all is fine so then I think it is very ... very like ... then I am calm... because you know you've got help. (Diane, mother)

It is absolutely great actually to be here. ... It is very good help. ... They are like little angels—the ones working here—and they are busy arranging for the ones who are here right and ... [I] think they are really good in trying to facilitate in the best possible ways for the children and for us and ... it is a bit hotel-like, despite the fact that you are in an isolate (Hannah, mother)

These parents experienced holding a two-fold role in being the one-caring and at the same time being the cared-for. Feeling cared for relates to the meaning of care as a relational phenomenon. Feeling cared for means to be able to "relax," be "calm," be "taken seriously," get "help," and be "met in a good way instead of feeling that one is a burden." It feels good to be cared for, and it stimulates the parents to care for the child in the ways that they prefer. As a cared-for parent, you can focus on being "just a parent," instead of being "a mom, a nurse, and a cleaner all at once." The nurses are described as "little angels" making the hospital stay "a bit hotel-like". For Kate, the collaborative aspect of the caring relation is important: "You know that they are here and like … I am the one who takes care of her and changes her nappies and those kinds of things … while they come in and do their things. … I can ask for help at any time."

#### Theme 3: Being in an Ambivalent Struggle

The majority of both parents and nurses who have administered medical treatment to children who resist experience caregiving as an ambivalent struggle:

[I experience] some mixed emotions because ... it was bad enough that he was hospitalized but then on top of that [I] ... have to force him to take medication. (Mia, mother)

I have to in a way... assist in that she gets the medical help that she needs ... but [laughs] at the same time I feel a bit rotten ... when I have to hold her tight while she is hollering and screaming and saying no. (Beth, mother)

I don't think it is okay to hold him in a vise like that [laughs] ... but it is nevertheless maybe a little necessary, I think. (Diane, mother)

Experiencing ambivalent struggle relates to the meaning of care as an intertwined bodily and relational phenomenon. The struggle is unwanted and elicits strong emotions, such as "bleeding mommy's heart" and a sense of guilt. Taking on a struggle with one's own child feels "nasty" and "sad," yet it is necessary: "you know you have to struggle" and "sometimes I have to hold her." Considering the caring relation between a parent and a child, ambivalent struggles can also raise issues of trust. Beth confirms this: "I am frightened that she will lose confidence in me."

Nurses on their side are also strongly affected by struggles:

It feels like a sharp pain inside of you. ... Sometimes, it feels like it borders ... [on] abuse, even though the indications are not the same, but they cry and think it is terrible ... and we have to do our utmost to make it as comfortable as possible ...and sometimes you can become frustrated and think that you don't want to this again and stuff like that ... and then you have to look at the whole picture ... and often one has to [do] things one doesn't like to make it become better again. (Eric, nurse)

With her [Karen] I didn't feel like the big bad wolf as I sometimes do when they really resist. (Karla, nurse)

When he [Harry] was protesting at his worst then I [felt] like a very evil person [laughs]. ... I mean ... he gets so angry, and it is like, 'Why are you doing that?' (Cornelia, nurse)

Nurses treat many children every day. When children strongly resist, it can create a strong impression that is bodily experienced: "like a sharp pain inside." The metaphors of "the big bad wolf" and an "evil person" also denote a clear ambivalence in care as a relational phenomenon—representing a contrast in how the nurse wants to appear as opposed to how the nurse perceives his or her own appearance. The reason for compromising the desired appearance is that the end justifies the means. One looks at the treatment in a more holistic perspective and is certain that treatment is necessary for the children to get better again:

When I see how much better they get from one inhalation then ... I think that the struggle is fair enough. (Cornelia, nurse)

Adults have to be in charge and it is in a way ... we have to help them... and it doesn't always feel okay, it really doesn't, but ... yeah... I don't find it difficult. (Anna, nurse)

And they [children with croup] are [experiencing] really narrow [airways], they are like, 'Ejjh' ... they are unable to get air down. ... It is obvious, of course, that you just throw yourself over this patient. (Anna, nurse)

Ambivalence emerges also in cases when nurses start to question whether the treatment is beneficial and necessary. One is cautious on behalf of the child's wellbeing and, for that reason, continuously assessing procedures:

And then I send a thought back to the physician again ... is it really necessary to have it [the procedure] every two hours? You become a kind of lawyer for the child, but at the same time, it is about me, too ... because it is like a struggle ... every two hours. ... Must we have that struggle every two hours? Okay, if we must. But if it is not necessary then I suggest we think it through. (Anna, nurse)

If they [the children] rage, then it is almost pointless because then they don't get any effect of the treatment either. ... So then it is almost like you just turn it off. (Laura, nurse)

On a relational level, caring means to see oneself as a "child's lawyer" who seeks to act in the best interests of the child and, therefore, questions the benefit of the procedures when children resist heavily. Struggles are also experienced as a bodily and temporal phenomenon:

You get worn out when you have to give many inhalations to one who protests for each and every ... but we manage. (Cornelia, nurse)

When they cry a lot and resist then it seems like it takes forever. (Karla, nurse)

Struggles are experienced as "exhausting" in a physical sense, but the experience of lived time is also affected: "it takes forever." Regarding lived space and relation, the difference between caring in theory and practice is also important:

It is very easy for a physician who is not actually standing in this situation to sit in theory and write it down. (Anna, nurse)

#### Theme 4: Finding Ways to Establish an Authentic Caring Relation with the Child

In all interviews, finding ways to establish an authentic caring relation with the child dominates. During treatment, establishing an authentic caring relation with the child is related to children's acceptance toward the treatment. Caregivers try to contribute to gained acceptance and trust through keeping calm, using conscious body language and physical contact, and shifting the focus toward something else besides the treatment.

I believe that if the person who is holding her is calm and it is calm around her, then she will experience it calmly and become more secure ... but I do not know if this is true; it is just the way I experience it ... that if I and we are calm and do not stress, then she will also not experience stress and stuff like that. (Leonora, mother)

I think it is really important that mom and dad keep calm. (Hannah, mother)

What is emphasized here is the importance of a calm bodily presence for establishing a caring relation with the child. Calmness can be attained in different ways:

I sing ... and then I hold them and I sit there and sing ... so that they become a bit interested in that ... to make them relax. ... They often relax with songs. (Anna, nurse)

A simple language and distractions through questions and taking a playful approach ... getting down on the same eye level ... not seem[ing] big and scary because it can seem quite threatening when someone is standing and talking down to you. (Eric, nurse)

Considering the relational level, parents and nurses try to make the treatment seem "less frightening" and "dramatic" through "making the best of it" and "doing what you can":

He is a bit more vulnerable and needs extra much comfort and cuddles and things like that. ... He needs much more attention than he usually needs. (Mia, mother)

We do our best to distract so it won't be such a dramatic experience for the children and the parents. (Bridget, nurse)

We talk to them ... try to use a calm voice, and we joke a bit and show them things that they like and that they can do. (Cornelia, nurse)

We use other means, too. ... We use dolls and parents ... as means... like mommy tries the mask, and I try it, and dad tries it ... and then you [the child] can try it a bit. (Eric, nurse)

To be close and hold a hand and ... breastfeed afterwards. (Diane, mother)

Through distraction, such as talking, singing, playing with toys, blowing soap bubbles, or watching a film, one can contribute with play and enjoyment. Through space as well as movement, caregivers can come closer to children during treatment and thereby also enhance children's acceptance toward the treatment. Regarding acceptance, the aspect of time is relevant. Time influences the experience of treatment:

The first time she got it, she really protested ... but now she is calm. (Christina, mother)

For me, everything is really okay because she doesn't make a fuss about it ... so it would have been worse if she would constantly cry and I would have to hold her [in a firm grip] like I had to the first time. ... That was really not okay at all. (Edward, father)

I think she actually understands that these inhalations are doing her good ... that she feels her breath is getting better, and you can kind of tell by the way she acts, like she is saying, 'Ohh ... this is really good!' (Kate, mother)

Time—and lived time—can be a way to acceptance and, thus, also a contributor to establishing an authentic caring relation with the child during treatment and hospitalization. Over time, some children seem to get used to the treatment, and some children seem to feel an immediate relieving effect of the treatment. Becoming familiar with the treatment influences children's attitudes.

## Theme 5: Understanding the Nebulizer as a Care Object

The nebulizer device affects the interaction between the children and their caregivers during the medical treatment. The device is the means for delivering the medication to the children and can, as such, be understood as an object with a caring intent. Yet the nebulizer device is often regarded as an unfriendly object, which children frequently resist and turn away from:

I don't think he saw it as a buddy. ... I don't think that the shape gave him any interest for either holding it or looking at it. (Andrew, father)

There is no interaction going on ... It is more like pushing it away [laughs] ... getting rid of it. (Beth, mother)

Some children find the nebulizer an interesting object, which must contain a different reason for not being able to use it as intended:

She tries to grab it ... look at it and eat it. (Christina, mother)

In other cases, the nebulizer seems to be accepted as a caring object:

She just lies there and welcomes it. (Kate, mother)

The relation between the child and the nebulizer device can change in the course of a single treatment or after a few treatments:

Usually it is okay in the beginning but then it lasts up to five minutes ... and maybe even longer ... and then they get impatient. ... They do. (Eric, nurse)

She doesn't care that much anymore ... so I think she's alright with it (Edward, father)

Several parents and nurses have concrete ideas about how the nebulizer can be improved to better fulfill its role as a caring object. The importance of reducing sound and time is essential. At the hospital, there are two different kinds of nebulizer devices available. The difference is essentially related to how the medication is vaporized—that is, either by compressed air or via ultrasound. The compressed-air nebulizers are noisy, while the ultrasonic nebulizers are almost soundless. At this hospital, the compressed-air nebulizers are few ultrasonic nebulizers are commonly used. However, there are a few ultrasonic nebulizers available at another ward, and these can be borrowed, if necessary.

I like it [the ultrasonic] better because it doesn't make sound, and I have used it on a child who really resisted, and when I gave her inhalation while she was sleeping and she didn't wake up, it was really worth it. (Karla, nurse)

We have borrowed it a few times, and I have a very positive experience with it [the ultrasonic]. ... It doesn't have that sound. ... It is less scary. (Anna, nurse)

I wish it didn't take so long. (Bridget, nurse)

Maybe ... if it would have been possible to make the treatment shorter ... because now it feels very long." (Laura, nurse)

The concerns about reducing sound, noise, and (lived) time can be understood as proposals to make the nebulizer a milder object envisioning it as an object that neither scares children nor requires their endurance. Besides these concerns, some also imagine that the nebulizer could be a more fun object—a medical product that can afford play and pleasure:

I think the shape in terms of color and music ... all such kinds of little details could have been more fun. (Andrew, father)

If it is decorated or it blinks or it has disco lights [laughs] ... then it kind of becomes more like a toy than a medical instrument ... which really can contribute to make it less scary ... quite simply. (Eric, nurse)

Understanding the nebulizer as a care object relates much to care as a bodily and relational phenomenon. Whereas the concern to reduce elements that can clearly evoke fear has to do with the lived body, the concern to add elements that contribute to play and joy has to do with the lived relation.

## Discussion

The aim of this article was to understand how human-centered designers could benefit from taking a phenomenological hermeneutics perspective for meeting stakeholders in healthcare contexts. Our entrance to better understanding the approach was to explore the phenomenon of care in the case of children's nebulizer treatment. In the following, we reflect on the care themes and on phenomenological hermeneutics as a human-centered design approach.

### The Phenomenon of Care in Children's Nebulizer Treatment

Based on interviews with parents and nurses, we constructed five themes that capture the phenomenon of care. The theme of feeling helpless refers to parents' vulnerability as caregivers in the situation. Experiencing helplessness especially relates to the meaning of care as both a bodily and relational phenomenon. A commonly expressed frustration was limited opportunity to directly influence the wellbeing of their child. The theme of feeling cared-for reveals how parents have a need for as well as experience care in the situation. Feeling cared for relates greatly to the meaning of care as a relational phenomenon. Parents experience that being cared for enables them to be better caregivers to their children.

The theme of being in an ambivalent struggle deals with experiences of administering treatment to children who resist. Both parents and nurses are strongly affected by struggles that can relate to the meaning of care as a bodily, relational, temporal, and spatial phenomenon. The theme of finding ways to establish an authentic caring relation with the child is concerned with how parents and nurses try to contribute to children's acceptance of the treatment. This theme has been connected to the meaning of care as a bodily, relational, temporal, and spatial phenomenon. The theme of understanding the nebulizer as a care object refers to parents' and nurses' experiences of using the nebulizer device and their ideas of how the device could improve as a caring object. This theme relates especially to the meaning of care as a bodily and relational phenomenon.

We suggest that the themes above can serve as inspiration for designers to reflect about their own role and experience of working with stakeholders. Different from other fields, for example user experience design, is that stakeholders' perceptions are not only evaluated by the designer but one's own experiences with the stakeholders become part of the evaluation and concept development. Including one's own attitudes and experiences explicitly can be seen as a novel method, also for iterating concepts. The themes are considered useful to elucidate the care phenomenon for the design community, rather than appearing as obvious pointers to design solutions. Phenomenological hermeneutics as method and epistemology broaden the understanding of care as a complex and conflicting phenomenon. Also, they make designers aware that not every aspect of care is "solvable" through a single solution. However, designers can, for instance, benefit from "borrowing" the feeling of helplessness to better understand a parent's relation to a child with a critical disease and how this relates to the use of a medical product, such as the nebulizer device. In a nutshell phenomenological hermeneutics trains designers to listen to themselves and to the stakeholders.

Focusing on the phenomenon of care is valuable in that it opens up for interpretion on how and what role a medical product plays in a caring relation. Especially when young children are expected to use a medical product, it is essential for designers to reflect on its potential as a caring object in addition to its medical purpose. In reformulating our question from the introduction, a designer with a phenomenological hermeneutics perspective will, instead of asking how medical products or services can be improved, rather ask the following question: How can we that is, the other persons involved and I—contribute to establish caring relations?

The nebulizer device is a central product in our case. This product, which is supposed to contribute to children's bodily wellbeing, frequently contributes to bodily and relational distress. We can reflect on Heidegger's notion of breakdown in relation to the themes. First, children's disease represents a breakdown of their lived body. This breakdown is also bodily experienced by the parents, as incorporated in the theme of feeling helpless. When children resist the nebulizer, this object also represents a breakdown-as equipment that is no longer "ready-to-hand" (Blattner, 2006; Heidegger, 2010). Rather, the nebulizer device is part of a treatment that both parents and nurses can experience as being in an ambivalent struggle-that is, a relational breakdown. People tend to enter into a creative dialogue when things do not function as intended (Koskinen & Battarbee, 2003). This is also reflected by the two themes of finding ways to establish an authentic caring relation with the child and understanding the nebulizer as a care object.



Figure 2. Prototype: (a) attached to nebulizer (b-c) designer demonstrates and (d-e) children's exploration. Photos and prototype design: Tori Klakegg Mæhlum.

One example of the latter is elucidated in the BLOPP project. The idea of the concept was to include the child and caregiver in the treatment through facilitating play, thus taking the meaning of care as a relational phenomenon as a starting point. Figure 2a shows the prototype, which is attached onto the tube of the nebulizer device, consisting of two handles and a flexible wire with a table tennis ball. When the mask is pushed toward the face, a switch inside the handle triggers a LED inside the ball to light up (Figure 2b-c). The ball also has a little bell inside.

Concerning the other themes, the prototype can constitute a shared focus of attention for the children and their caregivers. Such a shared focus can influence children's willingness to cooperate in the nebulizer treatment (Høiseth, Keitsch, & Hopperstad, 2014; Høiseth & Hopperstad, 2015) and might therefore in some way mitigate the parents' feeling of helplessness. Regarding the theme of feeling cared-for, the prototype can encourage the collaborative aspect of the caring relation during the actual medical treatment. As such, the prototype might also respond to the ambivalent struggles that parents and nurses experience by facilitating positive interaction based on play and pleasure and in turn it might contribute to establish an authentic caring relation by improving children's acceptance and trust. Some children have explored the prototype during nebulizer treatment at the hospital (Figure 2d-e). Preliminary analysis indicates that the prototype mediated meaning-making through shared exploration, play, and communication between children and caregivers.

Beyond this example, we suggest that there are many ways in which design can contribute to meet the challenges that are reflected in the themes. However, our intention is not to outline a range of different solutions in a recipe style. Rather, we acknowledge readers' own interpretations of the themes, and we hope that the resulting dialogue will contribute to enhance awareness toward healthcare experiences as an important purpose for design.

### Phenomenological Hermeneutics as Human-Centered Design Approach

This study challenged the authors' pre-understandings, such as designers have a special responsibility when it comes to adapting products that take part in medical treatment to the users. Our first notion of "the problem" in children's nebulizer treatment was limited to children's resistance toward the nebulizer device and wearing the mask. Through exploring the phenomenon of care, we have become more aware that there are, in fact, many aspects within the case that call for designers' attention. A typical designer impulse would be to immediately raise the following question: How can we meet these problems through design? We suggest that phenomenological themes are useful for dwelling on the complexity of people's lifeworld and, in our case, the complexity surrounding care in young children's medical treatment. The result of such a research is, then, to elucidate what a particular caring experience means for parents and nurses in order to learn more about how to design sensible products for children's medical treatment.

A practical research problem with phenomenological hermeneutics is that it is time consuming as a method compared to, e.g., document and literature analyses and some types of data collections. The time-consuming aspect can make phenomenological hermeneutics less feasible for design practice. We suggest that phenomenological hermeneutic studies also can be valuable as secondary source. Phenomenological hermeneutics is widely used in nursing research and can serve as an alternative entrance into the hermeneutic circle.

An epistemological challenge is that phenomenological hermeneutics encumbers the identification of general characteristics of products and services and that the phenomenological hermeneutics analysis (e.g., the themes in this article) can be called subjectivist and finally that results do not conglomerate individual and shared impressions of phenomena. This would make information imprecise and not easily communicated or put on trial. The challenge for phenomenological hermeneutics is to realize that even the most individual experience may, under certain circumstances, give access to phenomena of a truly shared character, such as emotional involvement in dealing with objects and phenomena (such as care) which are, although in several senses not at all new, certainly now growing in importance and quantity.

Finally, the phenomenological hermeneutics perspective is seen as a necessary supplement in human-centered design, where aspects connected to stakeholders' experiences are too often measured and averaged. The relation to the stakeholders and study participants is frequently one of detachment, and the focus on precise measurements may take over in favor of the concern for understanding what different measurements stand for. Assuming interpretation of products based on their highly individual experience means more or less abandoning the idea of patterns, implying a methodology where the focus is on engagement with stakeholders and their experiences, interpreting and developing an idea about what is important but not generalizing any findings.

## Conclusions

How, then, does phenomenological hermeneutics fit under the human-centered design umbrella? Regarding the methodology, phenomenological hermeneutics is coherent with a human-centered view, which rests on acknowledging human agency, competence, and participation. Phenomenological hermeneutics takes people's lived experiences as starting points for one's own reflection. Rather than delimiting people's opportunity to express and share their experiences, which is typically the case when using a survey or conducting a controlled experiment, phenomenological hermeneutics encourages the researcher to listen and learn.

The acknowledgment that multiple realities exist and that they are co-constructed mutually in processes that are individual as well as collective is valid for both human-centered design and phenomenological hermeneutics. On a methodological level, then, the principles on which human-centered design rests can be understood as fundamentally different from a positivistic worldview where the assumption is that a single truth exists, which can be identified and measured (Lincoln, Lynha, & Guba, 2011). Moreover, the relation between the researcher and the researched is not insignificant but quite the opposite-people do not simply share lived experiences because someone claims to be a researcher; rather, sharing parts of one's lifeworld is a matter of trust. Further research into social phenomenology is beneficial is this context since it allows to investigate different social roles of stakeholders, ways of experiences and interaction, and fosters corresponding and mutual trust building.

In the socio-political arena, phenomenological hermeneutics enables spreading people's voices and experiences to a larger community and contributes to participatory decisionmaking. This relates to the human-centered idea that people have a right to take part in shaping their environments. Experiences are co-constructed and involving people in learning from their lived experiences enables designers to understand that they are partners in the hermeneutic experience circle, too. Better appreciation for lived experiences can influence design decisions of an existing product or trigger exploration of new solution spaces.

Phenomenological hermeneutics can be understood as a supplement to existing methodologies within human-centered design. It offers a thorough exploration as "parts" and "whole" movement of people's lived experience and a designer's own understanding. Even if phenomenological hermeneutics overlaps with many of the human-centered approaches, such as participatory design and ethnography, we argue that its strength lies in the dedication toward lived experience as well as its methodological coherence with human-centered design principles.

Conclusively, in healthcare contexts, stakeholders typically interact with a range of different products and services. The study in this article elucidates one setting and gives references for healthcare context planning aimed at young children and their caregivers. We have provided an example of how research results relate to a physical prototype. Further research is needed to evaluate the use of the prototype in clinical settings and to provide implications for medical product design. Results showed also that for facilitating improved healthcare experiences, the human-centered designer can benefit by taking stakeholders' lived experience as a starting point for design. Even if lived experiences do not result in distinctive product characteristics, tools or strategies for making stakeholders buy a product, it indicates how stakeholders interact with things and if they enjoy this interaction or not. Phenomenological hermeneutics is a starting point for thinking design iterations differently.

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