"IT'S NOT THAT IT WILL KILL ME": LIVING WITH ELECTROMAGNETIC HYPERSENSITIVITY

ARTICULATIONS, NEGOTIATIONS

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ABSTRACT

While the future visions of Internet of Things are slowly being implemented, the wireless and networked infrastructures that enable these connections already intervene and matter in people's everyday lives in powerful ways. In this paper, we present a case study of a woman living with electromagnetic hypersensitivity; the heightened sensitivity of electromagnetic fields. We describe how her daily activities and everyday habits are both enabled and constrained by digital technologies. Through this narrative, we reflect on how this case has impact for design research regarding how the objects we design matter in people's everyday life in unpredictable and uncomfortable ways - also those that are not wirelessly connected.

INTRODUCTION

With the domestication of information technologies, an increasing number of designers use the immaterial and digital medium of computation as design material. Algorithms, data, apps, devices, sensors, motors, software and hardware are all aspects of computation that enable and constrain everyday activities in people's lives. Digital-enabled objects are often described with the prefix "smart", by which it is implied that when analogue objects can track, record or monitor its surroundings and hereby help manage and optimize people's everyday activities, it results in a "smarter", and thus better, everyday life. Smart objects make our cities and homes "smarter", but as highlighted by this year's Nordes call on Design + Power, these objects "are presented as givens [and] are emerging rapidly, with relatively little critique and social or cultural analysis".

In this paper, through sharing the story of Ingrid, we aim to critically reflect on how the smart objects' infrastructure matters in people's everyday life. Ingrid is a retired woman living in Umeå, the largest city of Northern Sweden. Ingrid is like most of us, but her electromagnetic hypersensitivity (EHS) makes her different.

Every time Ingrid uses technology it is a conscious choice. She negotiates between the benefits and needs of using technology *and* the painful bodily symptoms this brings. In medical science, the validity of the EHS symptoms is still disputed but it is not relevant to this article whether or not the condition is scientifically validated; we care about her experiences, not her diagnosis. Ingrid's story serves as a case of a modern technological life: How technologies intervene and adapt to people's everyday life, but also how people adapt themselves and their homes to technologies. Her case allows us to reflect on how we take technology as a given and how we all live with technology despite it not always being to our advantage in all regards (emotionally, physically and environmentally). We especially want to show how the objects we design exert power on people's everyday life, also of those lives that are different than Ingrid's.

Figure 1: WiFi router hidden inside a closet in Ingrid's home in Umeå, Sweden.

HERTZIAN SPACE AND WIRELESSNESS

EHS is a heightened sensitivity to electromagnetic fields (EMF); symptoms include headache, stress, skin prickling and fatigue. The symptoms are real, however science declines that they are caused by EMF (Belyaev 2016). Still, health authorities, politicians, and courts of law are starting to recognize the interactions between EMF and health problems, and reports indicate that new wireless technologies raise new challenges for medicine and society (ibid). There is mistrust towards the real health risk of EHS and popular culture often depict people suffering from EHS as eccentric, such as the character Chuck in the American series "Better Call Saul".

Attention towards electromagnetic fields has been a recurring part of design research the last 20 years. Design researchers Dunne and Raby not only coined the influential term Critical Design, they also investigated how the increasingly networked surroundings have impact for design research (Dunne & Raby 2001; Dunne 2005). "Hertzian space" describes how electromagnetic fields take up physical, yet invisible space. Directing attention to the possible sensual and poetic experience of hertzian spaces, designers are encouraged to work with "the poetic and multi-layered coupling of electromagnetic and material elements to produce new levels of cultural complexity" (Dunne 2005: 121). Reflecting on the historical power structures of hertzian spaces, being shared by military, the state, commercial companies and community-based organisations, as well as the impact of hertzian spaces on people's everyday, Dunne & Raby writes: "In the near future, more of us may feel the effects of the inevitable increase in usage of the EM spectrum. Hypersensitive people are the pathfinders for this changing environment, 'human canaries' alerting us to dangers and concerns that are bound to become more common as more technology becomes wireless" (Dunne & Raby 2001: 36).

Wireless technologies intervene into our life even if we notice only fractions of it (Savic 2014). The entanglement of objects, infrastructures, networks, and bodies creates new site-specific experiences of being connected, which might better be understood through the term 'wirelessness' (Mackenzie 2010). While the embodied experience of wirelessness is most often noticed when technologies are not working as expected (Grönvall et al. 2016), wirelessness is an ever present, haunting part of a modern technological life. IoT, smart homes and smart cities increases this feeling (Greenfield 2013), but we still only understand and take designerly advantage of fractions of it.

Through the story of Ingrid, a woman living with EHS, we reflect on how we might better understand the socio-cultural as well as the technical aspects of wirelessness.

TECHNOLOGIES IN EVERYDAY LIFE

In interaction design, and especially when adapting a participatory design approach, ethnographic inspired studies are conducted to better understand people and their needs and use of technologies, and how new technologies might be developed to support their needs. The study of how people incorporate everyday objects into their routines and homes, and how objects change the way we live in our homes, can e.g. inspire new perspectives on tangible and embodied interaction (Brereton 2013). In an ethnographic study, Brereton visited an elderly woman to understand how everyday objects are adapted, appropriated and habituated to suit her living for the past 15 years. Under the term "habituated objects", she describes the intimate relations that arise between humans and objects and the routines and rituals that follow in the home. But as described in "Making by Making Strange", studying the home is difficult (Bell et al. 2005). Because the home is so familiar, it implies asking questions about what seems to be obvious. Bell et al. argue that through defamiliarizing the home it becomes possible to open the home as design space (ibid.). This points to an inventive ethnographic method of studying the home.

In "Implications for Adoption", Lindley et al. argue for the importance of not just developing new technologies, but also speculating and exploring technologies' potential adoption in the future (Lindley et al. 2017). Lindley et al. argue that design fiction may be a method to better understand the "nuanced, situated, and technologically-mediated relationships that innovative designs facilitate" (ibid.). The speculative nature of design fiction is closely related to future-making practices of design anthropological futures (Smith et al. 2016), speculative design (Dunne & Raby 2013) and speculative fabulations (Haraway 2015). In "A Curious Practice" Haraway describes the practice of visiting as a curious yet risky practice. Visiting, she argues, implies that the researcher is open towards the unanticipated and stimulates the unexpected, e.g. through speculative narratives (Haraway 2015).

Even if the aim of this study has not been to design new technologies, design's interventionist and speculative character has still informed the ethnographic approach. As such, the design ethnographic study of Ingrid's everyday life has played out in the intersection of (early) critical design's focus on "hertzian spaces" and the perception of wirelessness, and present speculative and participatory approaches to defamiliarizing the home and futures of the (smart) home.

PROBING EHS

What began as a three-month sublet in Ingrid's house, soon turned into an inquiry into her way of living with EHS. The first author is a PhD student researching and designing intimate wireless technologies from a critical and feminist perspective, and she soon became intrigued and curious about her landlady's way of living. The empirical study was inspired by design anthropology (Smith et al. 2016) and by critical and feminist research-through-design (Bardzell & Bardzell 2011, Koskinen et al. 2011). The study included three entangled phases: 1) the ethnographic study, 2) the material exploration through cultural probes, and 3) the interpretation of the documentation and the returned cultural probes.

Through sharing her house, the first author followed how Ingrid negotiates the EHS condition and a modern technological life. In seeking to discuss the complexity of her everyday habits and negotiations between connecting and disconnecting, we conducted an informal interview where Ingrid also showed her most and least favourite objects and activities in her home. The interview was documented through doodles, audio recording, photos and video material. In addition, we prepared a cultural probe kit, the aim of which was to capture more unconscious aspects of Ingrid's everyday life and to keep in contact after the first author moved away from Ingrid's home (Gaver et al. 1999). Finally, part of the study of Ingrid's perspective on the world has also been the visual analysis and visual editing of video and photos that we present in this paper.

THE CULTURAL PROBES

In preparation for the interview we made a cultural probe kit including a map for mapping EHS in Umeå, three postcards with pictures of Umeå taken by the first author, and a "wifi piece" poem; a poem inspired by Yoko Ono's conversation pieces that stimulate reflection on everyday activities (fig 3). The kit was introduced during the interview and aimed to sustain the conversation also after the first author left Umeå again.

Figure 2: The cultural probes.

Figure 3: The postcards that Ingrid received during the interview and was asked to return after the first author moved out of her house.

THE INTERVIEW

The interview with Ingrid lasted two hours. In the first hour, Ingrid told her story about living with EHS; how it feels, how it has developed the last 40 years, how she maintains an everyday life, and how family, friends and society perceive her condition. During the interview the first author made doodles to represent what Ingrid told. This became a visual documentation of the story and what the first author picked up on. Sometimes Ingrid responded to this, e.g. when she asked if the stick man in the upper left corner was her. The stick man represents that she is wearing a cap when she goes to a

building with a lot of old strip lights. Other doodles represent her experiences of working in a school, her problems with flying, how EHS feels in Umeå compared to Oslo and Spain, and how she still goes to cafés with WiFi to have "fika" (a Swedish concept for the social culture of having a break with coffee and cake) with her friends even though it means she has to rest when she comes home. Halfway through the interview, the first author gave Ingrid the cultural probes and a "wifi piece" poem, written to Ingrid. Ingrid read the poem together with her husband, we talked about the cultural probes, and after this Ingrid showed us around her home.

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WIFI PIECE

Feel the space.
Feel the electromagnetic space.

Walk around the space.
Walk to the place where you feel less tense/friction.
Walk to the place where you feel most tense/friction.
Walk back.

2016 winter
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Figure 4: "WiFi piece" poem and doodles made during the interview.

THE STORY OF INGRID

For most people, electromagnetic fields go unnoticed. We seldom think about whether we sit too long in front of a screen or if the café where we will meet our friends for coffee has WiFi. For Ingrid, hertzian spaces are an inherent and conscious part of everyday life. She navigates the city and performs daily activities, such as watching television, scrolling the Internet, or shopping groceries based on her bodily experiences of hertzian spaces. After living in the same city her whole life, she has learned to navigate the urban wireless landscape. Similarly, she has adapted, appropriated and habituated her home to suit her condition by making unique solutions to EHS-proof her everyday life. She has learned to take control of her condition, and balance a modern technological life with the EHS symptoms. She

does not escape the digital society but has adopted technologies based on her special needs, and learned what she wants, could and what she should (not) do. This we present and discuss here.

BODILY SYMPTOMS
In one of the postcards Ingrid writes about a mundane day with EHS:

> Tell me about your day with EHS.
>
> *Hey M-L!! Swollen eyes (it looks like I have been partying all day yesterday). A feeling of fever in the body and pain in the joints. Tired already after breakfast and the best is to go for a stroll in the "fresh" air. My mucosas are dry and I have a pressure above the eyes – forehead, headache. Tired, tired. Good luck with your research.*
>
> *Take care / Ingrid*

Figure 5: The second postcard we received from Ingrid.

In the postcard, Ingrid describes the symptoms she felt but not exactly what caused them or in which situations she felt them. The next section unfolds which objects that cause Ingrid's symptoms but let's dwell with two things Ingrid writes: 1) the quotation marks that emphasize the air as "fresh", which either points to the importance of nature *or* the irony of how also "natural" spaces are occupied by EMF, and 2) the last greeting, which points to the personal relation between the first author and Ingrid; one of mutual trust and care.

OBJECTS IN INGRID'S HOME
During the interview, Ingrid took us on a tour to the most and least favourite objects or activities in her home. Ingrid's home is her "EHS-safest zone". It has been adapted to her needs, e.g. electricity has been grounded. Still the air is filled with microwaves, TV-frequencies, etc. In dealing with these hertzian spaces, two of her favourite objects are the air cleaner that cleans the air from bacteria and the dust cleaner that removes the dust that has been attracted to the electronic devices. Another of Ingrid's favourite things is candles, e.g. the Advent wreath that she likes to light during the dark December in Northern Sweden. While candles are cozy, many people also consider them harmful to the indoor climate and health, because of the toxic chemicals that are spread when they burn. However, from Ingrid's perspective candles are great because unlike light bulbs, strip lights and LEDs, candles do not disturb her body with electricity.
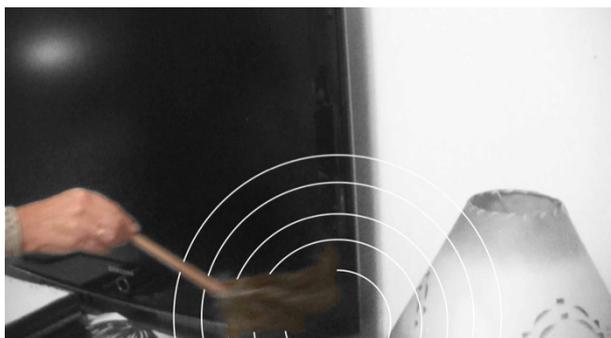
Figure 7: These are a few of Ingrid's favourite things: candles, air cleaner and dust cleaner. In addition, Ingrid likes to spend time outdoors, dance and listen to music; all activities that do not require electricity.

When Ingrid was asked to show her least favourite objects she pointed to her iPhone, television, microwave oven, WiFi-router and computer. However, one month later when she returned the postcard with the question "Tell me about your favourite digital thing", she told us about her relationship to her computer.

Figure 8: The first postcard we received from Ingrid.

Figure 9: Ingrid pointing at her EHS-safe personal computer.

This points to the complex condition of wanting to use a technology even if it is "dangerous" to your health. In order to use the computer for information, administration and keeping in contact with family and friends, she has acquired an EHS-friendly screen. Ingrid's EHS-condition became worse when computers entered the school where she worked 20 years ago. It became a problem to have an administrative job but now that she has a screen customised for people with EHS she likes to use her computer. WiFi is usually turned off and she uses a cabled Internet connection. One of the few times she turns on the WiFi-router in her home is when her smartphone needs a software update or when her now adult children are visiting.
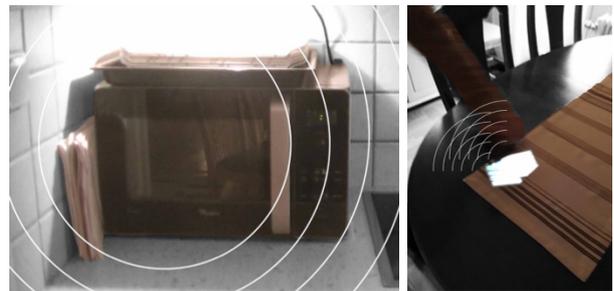
Figure 10: These are a few of Ingrid's least favourite things: microwave (left) and her iPhone (right).

In Ingrid's home, the WiFi-router is hidden behind boxes and paper in the back of the utility closet in the kitchen. In collaboration with her husband, she has created an analogue homemade WiFi (warning) system that both warns if the WiFi is turned on and makes it easy to turn WiFi on/off. A red plastic peg on the shelf is pulled down to signal that WiFi is turned on, and an electrical switch makes it easy to turn on/off the WiFi-router without having to come close to the WiFi-router and remove the cardboard boxes that are placed in front of it, next to foil and kitchen rolls. Both Ingrid and her husband are proud of this creative solution.
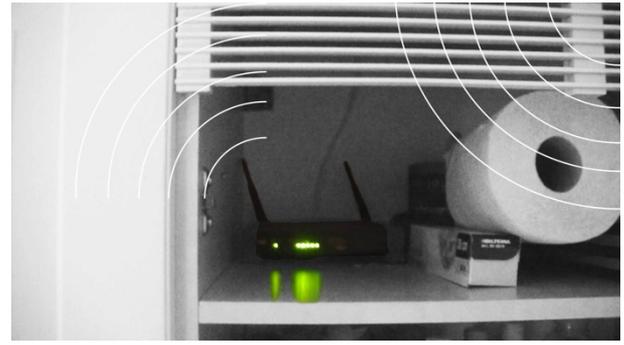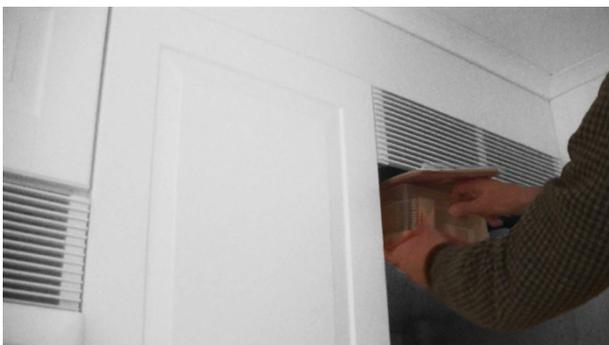
Figure 11: The self-made WiFi-router system.

THE CITY LANDSCAPE

As part of the cultural probe kit we asked Ingrid to map the spatial experience of EHS in Umeå. A week after the interview, Ingrid returned the map including a list elaborating on the blue and the white dots. The blue dots represent areas with much electrical tension: areas where she cannot stay without feeling sick. The white dots represent areas with little electrical tension: her "safe-zones". The map portrays the ubiquitous feeling of wirelessness in a city. With a ratio of 20 blue dots versus only four white dots, it shows how Ingrid's navigation in the city is a constant negotiation between entering "dangerous" public spaces and institutions, or "staying safe" in more private, homely spaces. The map thus portrays the embodied, memorized, spatial knowledge of how a woman living with EHS enters and navigates her city:
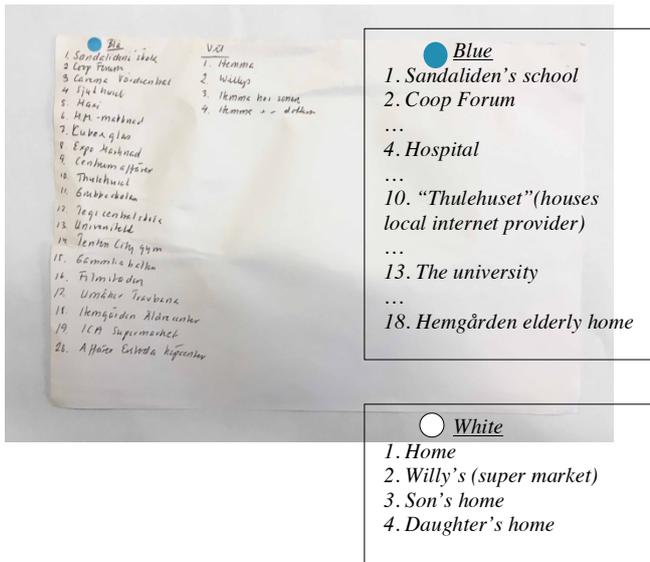
Figure 12: The instructions given to Ingrid and the map and list of areas where she feels much/little tension.

DISCUSSION

In this case study we have used design ethnography to explore how a woman living with EHS balances her condition and a modern technological life. Ingrid is more conscious than most people about her everyday use of technology and about how she has adapted technologies in her home. We have sought to uncover her domestic and urban routines through the interview, and defamiliarize her habits through the cultural probes. Ingrid's story is important as a case study of how people living with EHS adapt technologies in their everyday life but the case also has a potential to uncover more broadly, how we all adapt to wireless technologies and perceive wirelessness as a haunting part of everyday life.

Future visions of smart cities, smart homes and IoT are often represented in visually appealing scenarios. However, the success of this vision depends on the wireless and networked infrastructure; that it enables objects to connect without harming our bodies and environment. Already today, wireless technologies intervene and matter in people's everyday, and like Ingrid we all try to navigate our use through everyday negotiations, appropriations, life hacks, or self-made systems. Some of us make rules for how we spend time in front of a screen, for when and how we are online, for when smartphones are put away, or maybe we sometimes explicitly favour analogue, non-connected solutions. An increasing number of connected everyday objects and services prompt us to continuously renegotiate our habits and priorities. As in the case of Ingrid, this development does not hold a simple question and solution. Ingrid herself said during the interview, "it's not that it will kill me, but...".

We manage, negotiate, and habituate our technology use. We care for our health (emotionally, physically, environmentally) and for what we should (not) do, but we also embrace new smart products that promise to improve our everyday lives. The case of Ingrid portrays how this (power) relation between people and technologies is entangled with discursive logics and politics (Barad 2003): how internet-infrastructure, nature, diagnosis, identities etc. operate and how these materialize in bodies and in people's everyday lives. The haunting experience of wirelessness in today's society shapes everyday life from the personal to the commercial, the social and public. In Ingrid's case, wirelessness affects how she perceives herself and develops her identity: as someone living with EHS. Secondly, it affects how she behaves as a consumer; she avoids new smart objects but is still constrained by e.g. the iPhone's business model demanding people to continuously update their phones. Thirdly, is affects her social life and how and where she can join her friends and family. Lastly, it affects how she is perceived by the system; whether or not her condition is medically approved and she can get help and support.

CONCLUSION

Nowadays, almost all digital technologies are wirelessly connected. Through the case of a woman living with EHS, we have described how everyday habits and negotiations of use are an inherent part of interacting with and adopting technologies. Ingrid's story shows how the objects we design exert power on people's everyday life, also of those lives that are different than Ingrid's.

Ingrid performs daily negotiations in order to not feel ill, and we have used this case study of EHS to raise awareness towards the invisible and powerful effects that wireless technology might have on us, and how we all are a part of this taken-for-granted infrastructure. We are not taking a stand in the debate of EHS as a medical condition, neither are we arguing that Ingrid's story is only relevant to those that wish to design for people with EHS. However, with an increase in wireless technologies it is increasingly important to reflect on the experience of wirelessness in our homes and cities, and how we can take designerly advantage of this. And in this quest, Ingrid is an excellent case because she acts consciously to everything wireless.

This paper contributes to discussions of how we as design researchers might broaden our ways of understanding, discussing, and designing the complex lives of those that live with wireless technology, even when they are less sensitive than Ingrid. This design ethnographic study is a first step in that direction, in that it has contributed with a nuanced understanding of the impact of wireless technologies in everyday life, and how such wireless technologies are adapted in the life of a woman living with EHS.

FUTURE WORK

Hertzian spaces have been part of the critical discourse of design for many years. This study of Ingrid is an example of how people with EHS are now even more

affected by the electromagnetic fields of wireless technologies. As such, the study has manifested the conceptual thoughts presented by "Hertzian Tales" (Dunne 2005) in Ingrid's mundane everyday life. With speculative and critical design's sociocultural concerns with futures, it seems important to follow up on its past concerns. According to Dunne, hypersensitive people are 'human canaries' "alerting us to dangers and concerns that are bound to become more common as more technology becomes wireless" (ibid.). Ingrid is one of such 'human canaries' and EHS is still a growing concern. With a growing wireless infrastructure it does not become less important to understand what wirelessness feels like, even if we can't all sense it. As Ingrid said, "Today I'm considered a bit unusual, that I am so sensitive to this, but maybe it's different in 50 years. I'm just a bit ahead".

To continue and build on this work, more research into people's everyday life with wireless technologies needs to be done, including those lives that are not affected by EHS. This study did not aim to propose solutions to this complex issue, but rather to understand its nuances, and as such there is still a need to develop research into more designerly ways of intervening into hertzian spaces in the home as well as in the city.

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