Sense-Making in Complex Healthcare Domains: The Role of Technology in Every Day Lives of Youth Suffering from ME/CFS

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Abstract—**In this paper, we argue that the technology design needs to take a more holistic perspective, well beyond opportunities offered by the technology development alone. This is especially important when developing technologies for complex domains, such as healthcare, and with users who are at risk. We propose a sense-making process that helps human-computer interaction researchers/designers to develop a broader understanding of such complex domains in which they often have no expert knowledge. We exemplify our approach by exploring the complex domain related to the design of technologies that could support youth with Myalgic Encephalomyelitis to cope better with their situation. The approach is based on a combination of user research, Actor-Network Theory adapted to the design context, a complex systems design tool (Giga-mapping) and a literature review. We find that this approach leads researchers to reflect deeper over the domain complexities, and to avoid solving problems that do not untangle complexity or lead to real-life solutions. Our conclusion is that such initial sense-making processes are fundamental when considering the design of new technologies for healthcare, and with vulnerable users.**

Keywords-complex systems; sense-making; ME/CFS; ANT; healthcare; design thinking.

I. INTRODUCTION

Diverse self-management applications and technologies that aim to support people in improving and maintaining their quality of life, or helping them through an illness and a recovery process, are increasingly sought after within healthcare and addressed through Human-Computer Interaction (HCI) design and research. However, these applications are frequently developed without sufficient understanding of the complexities of the healthcare and problems within this domain that are often wicked [1]–[3]. Wicked problems have been discussed by Rittel and Webber already in 1973 [4], but have gained more attention lately through the use of design thinking, e.g., [5]. Wicked problems are incomplete, contradictory, changing and interdependent. Working with them is difficult, and is often relinquished too fast in favor of finding a good solution to some problem. Finding real design opportunities and problems to solve may then be lost. The design of healthcare technologies that support users and fit well the context of use require a broader and deeper inquiry into the nature of problems and their relation to the situated design space [6].

In this paper, we discuss the initial sense-making in complex domains, a process that enables this broader and deeper understanding of the context, and design options. As an illustrative case, we use the design of supportive technologies for a particular user group, adolescents suffering from Myalgic Encephalomyelitis (ME), often referred to as the Chronic Fatigue Syndrome (CFS), or ME/CFS. Almost no research results were to be found on this topic. Without a-priory knowing what kind of solution(s) to offer to these users, be it self-management tools, or other systems or services that could be useful in their everyday lives, we propose a framework for sense-making and finding problems that are meaningful to solve in this context.

In recent years, the increase of chronic diseases, in particular among youth, has been significant [7]. Among these diseases, ME/CFS has become a growing concern, not only for those suffering from it and their families, but also for the medical science, governmental health management, and society at large. Tweens and adolescents who are affected by the illness, would be, if healthy, considered to be willing adopters and users of technology [8]. However, even for their healthy peers, intensive use of technology may lead to negative health consequences [9]. Thus, for those with ME/CFS, it is crucial that technology does not introduce a new set of problems or worsens their health condition [10].

From this perspective, we consider youth with ME/CFS to be a group of vulnerable users [11]. Vulnerability is to be understood as a set of risks that these adolescents are exposed to. Understanding these risks, and how to reduce or eliminate them, is a step towards understanding design and technology design spaces when considering designing for and with this user group.

Furthermore, the understanding of the design space in complex contexts may require understanding of several different fields pertinent to the context. Understandings can be at the micro-level (e.g., how a specific solution affects the user) and understandings at the macro-level (such as social, cultural and governmental influences on the design space). In a development of supportive technologies for and with youth with ME/CFS, we have chosen to use Actor-Network Theory (ANT) to produce rich descriptions of the interrelated social and material processes [12][13], Giga-mapping to represent and communicate our thinking about design, and finally, a firm focus on users and use. We argue that such combined approach helps researchers to develop and communicate growing insights efficiently, become aware of the broader

range of issues and their interconnectedness, engage in more innovative designerly practices and reflect critically on own position and values in the sense-making process. When using Design Thinking (DT), an HCI researcher typically adopts designerly practices when making prototypes. The difference between a research prototype and a product in use is significant [14], as are the implications for knowledge production [15]. When working with wicked problems in complex domains, an HCI researcher needs to work with his/her own mindset and develop an ongoing sensibility and sensitivity to problems inherent to the context.

The paper is structured as follows: we provide the literature review in Section II, followed by the section on ME/CFS and technology design. Section IV combines our findings and discussion around technology for adolescents. Finally, Section V presents our conclusions.

II. THE LITERATURE REVIEW

For the case presented in this paper, we started by mapping out our understanding of the context, see Fig. 1. The purple area in the center of the figure represents users for and with whom we aim to find and design solutions that could support them. To do so successfully, understanding what it means to be an adolescent with ME/CFS is crucial. This understanding is often referred to in the literature as an empathy with users [16]. We, however, believe that going beyond empathy, and venturing into the understanding of scientific, in our case medical, results related to the condition is also necessary, even when outside of our field of competence. These medical results, for example, could help to find a broader set of risks those adolescents with ME/CFS experience. Naturally, HCI and designerly thinking, being our own and familiar practices, are a fundamental ingredient in this process. ANT, as it applies to design and designers [13], is chosen to represent cultural, governmental and educational perspectives.
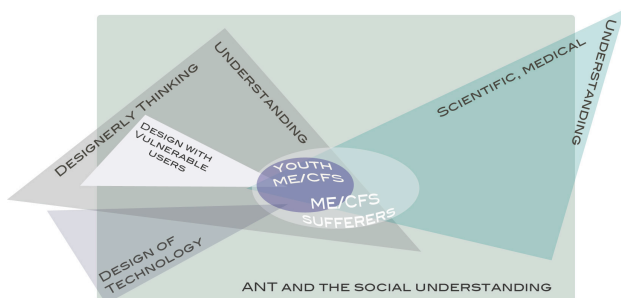

Figure 1. Giga-mapping fields of concern for design related to ME/CFS.

In what follows, each subsection represents a short summary of literature findings related to areas depicted in Fig. 1 that became the starting point for our sense-making.

A. A medical understanding of adult and paediatric ME/CFS and its effects: the challenging nature of the disease

ME/CFS, is a debilitating multisystem illness resulting in a plethora of symptoms that include severe physical and cognitive exhaustion, confusion, difficulties with memory, concentration, sensitivity to light and noise among others, see [17], [18]. What causes the illness remains an enigma, and the condition is presently researched on a broad scale, e.g., [19]. Many theories, ranging from viral infections to psychological stress have been proposed [17]. Some studies suggest that the immune system may be chronically active in CFS sufferers. This might relate to a theory that ME/CFS is caused by an abnormal reaction to common infectious agents. This theory could link ME/CFS to autoimmune diseases such as the Lyme disease and the Epstein-Barr virus.

A review of thirty-four qualitative studies on ME/CFS, see [20], was done and the authors find that *"For sufferers, illness development influenced identity, reductions in functioning, and coping. Physician-specific themes described lack of awareness about ME/CFS and recommended improvement in educational resources. Intersecting themes expressed issues with diagnosis creating tensions and fueling the stigmatization of ME/CFS"*. Also, some research points in the direction where sufferers themselves help to perpetuate their condition. For example, Afari and Buchwald state that *"current knowledge about chronic fatigue syndrome suggests that genetic, physiological, and psychological factors work together to predispose an individual to the condition and to precipitate and perpetuate the illness"* and, further, that *"sufferers' perceptions, illness attributions, and coping skills may help to perpetuate the illness"* [17, p. 230]. Such results, unless verified carefully, may help to perpetuate stigmatization. Other research, such as that of Geelen et al. [21], or Winger et al. [22], offers insight into personality issues relevant for understanding the youth suffering from ME/CFS.

The treatment of those suffering from ME/CFS is highly individualized, frequently symptom-based, and includes both pharmacological [19] and behavioral approaches [23]. The most common form of help to those suffering from the illness in Norway [24] are self-management courses, offering guidance on how to stabilize the symptoms, find a balance between rest and activity, adjust to a life with ME, etc. This is in line with the trend to promote self-management wherever appropriate for sufferer care, and especially so for sufferers with chronic diseases [25]. Self-management often involves the management of medical conditions, behavior or emotions [26], [27]. For users with ME/CFS, self-management also includes the management of so-called *energy balance*. An ME/CFS sufferer is considered to have a limited amount of energy available for use per day. If an activity takes too much energy, the overuse results in extra exhaustion over a period of time lasting from several hours to several days, leading to increased pain levels, sensitivity and overall worsened physical and cognitive condition. The problem is often that a person with ME/CFS does not know what amount of energy is required for an ordinary activity such as, for example, meeting a friend for a cup of coffee. Therefore, the energy balance management is difficult.

A user study carried out by the Norwegian ME/CFS association [18] found that 40% of people suffering from ME/ CFS did not receive medical help with relieving

symptoms caused by the illness. When sufferers were asked what kind of help they would like to receive from the healthcare sector, the results indicated professional assistance with sleep problems, stress management, stomach problems and general pain relief.

For children and youth, the situation is additionally difficult because it is harder to make their voice on the matter heard:

"Do children and adolescents suffer from ME/CFS? Simple common sense tells most parents, teachers and doctors that they do and often more severely than adults. Yet there remain a sizeable proportion of professionals in Health Care, Education and Social Services who are still prepared to ascribe the numerous, disabling but seemingly unconnected symptoms of this illness in young people to anorexia, depression, school phobia or a dysfunctional family background. All are, at least, agreed that the illness presents a considerable economic, educational and social problem" [28].

Resonating with these findings, and in part, because the illness does not leave visible marks on a person suffering from it, they are often dismissed as suffering from psychological problems, or worse, stigmatized by general population [20].

The sufferers from ME/CFS have to bear the medical uncertainty of what causes the disease and, as a consequence, absence of an effective diagnostic tests and treatment for the illness [29]. Furthermore, ME/CFS social and political uncertainties related to the disease are of undetermined duration, depending most strongly on scientific, medical findings around the condition. The youth is affected by nearly the same rates, from about the age of 11, as adults [30].

For someone to be diagnosed with ME/CFS, the symptoms need to be present to such a degree that they clearly limit a person's ability to carry out ordinary daily activities [31]. Sufferers are classified into four groups: mild (an approximate 50% reduction in pre-illness activity level), moderate (mostly housebound), severe (mostly bedridden) or very severe (totally bedridden and in need of help with basic functions) [32].

B. Previous research on ME/CFS in adolescence and technology

As mentioned in the introduction, there is very little in the literature on assisting people, including adolescents, suffering from ME/CFS through the use of technology. ME/CFS sufferers, as mentioned above, have multiple challenges, at the physical and cognitive level, coupled with reduced tolerance to light and noise. They, thus, may not be the prime candidates for the use of screens for receiving information, whether they are smartphone screens, tablets or personal computers. All the solutions mentioned here are screen based. While screens may be a good option for adolescents in general, they may have limitations for those with ME/CFS. Thus, before deciding on any new solutions for these adolescents, one needs to make sure that proposed solutions do not introduce new problems and health risks.

From the literature survey, we found that social isolation and access to education are important for these users. Several research efforts point in these directions, studying either the social media or platforms for education. General use of social media in medical care was described in [33], where authors have analyzed and synthesized 76 articles, 44 websites, and 11 policies/reports and presented findings according to 10 different categories of social media such as blogs, micro blogs, social networks, professional networks, thematic networks, wikis, sharing sites and others (represented by the Second Life). Findings, in particular those related to the second life are relevant for adolescents with ME/CFS and have been taken further in the work of Best and Butler [34], [35]. The paper [35] describes how a virtual support center was constructed in the Second Life, featuring meeting areas, relaxation areas, library resources and a gallery of art by and for people with ME/CFS. However, the results of the investigation gave mixed conclusions, possibly reflecting the fact that certain level of mastery of the virtual environment was needed, and that was not possible for all users to accomplish. Also, a physical and cognitive condition of ME/CFS sufferers may affect their willingness to dedicate energy to learning about new virtual environments. The Second life application, in addition to providing information related to the condition, was aiming to address loneliness and social isolation.

Considering the educational platforms for ME/CFS sufferers, the paper on e-learning, [36], can be brought forward. In this study, e-learning platforms were explored as an opportunity for children with ME/CFS to participate in classroom activities even though they are staying at home. As the authors state, this is especially relevant to Scotland, where many live far away from schools. However, the access to school and educational materials is only the first hurdle in receiving regular education and does not address other problems that youth with ME/CFS often have.

C. Design Thinking and Design with and for Vulnerable users

Design Thinking may be defined in many different ways. For example, it may be defined as a process that fosters innovative and creative thinking [37], or as an approach to mitigate complex problems through design [5], [38]. In [39], the authors also include the important discussion on the role of design research and designerly practice, with core concepts that include reflexive practice, meaning making and designerly ways of knowing. When working with vulnerable users, it is important to take into consideration ethical concerns as part of the reflection, and meaning making that ideally includes real users or those who represent them well.

While the screen-based technology can play a supportive role in providing care for many users, the ME/CFS sufferers may have a very limited ability to concentrate, read, or even just look at a screen. ME/CFS adolescent sufferers are perceived as vulnerable also on being at risk of not using technology because of how their diverse illness symptoms limit their capabilities (physical or cognitive). In [10], authors argue that the term 'vulnerable' imply a set of risks.

When identified, the risks could be helpful in defining design goals that aim to reduce or eliminate risks. They further argue *"the awareness of risks/vulnerabilities in a design situation may be helpful in designing better products for vulnerable people"* [10, p. 3]. These and other design concerns in design for and with vulnerable users need to come forth through a sense-making process.

We find Giga-mapping [40], to be a particularly useful tool for sense-making in complex contexts. The Giga-mapping aims to facilitate thinking and communication, at the same time inviting (basically by its large physical space) participation and collective production of understanding of the design context. Giga-mapping can be used to visualize fields of knowledge, as was done in Fig. 1. Furthermore, the complexity of a problem space can be mapped out, for example, in layers (e.g., understandings on micro, mezzo, and macro levels), fostering further understanding of complexity and relatedness of problems.

D. Theorizing technology and Actor-Network Theory (ANT)

As this research aims to understand a larger, holistic picture around ME/CFS sufferers and technologies that could support them in their everyday lives, we propose the use of a pragmatic ANT inspired analysis of design opportunities in the initial, sense-making phases of a design process. To that end, a short overview of ANT is provided.

ANT can be used as a framework to understand a heterogeneous network consisting of diverse human and non-human actors. ANT is different from other social theories applied in information systems research, in how it helps to theorize the technology artefact, by focusing on both the social and the technical [41]. In ANT all the social-technical elements are included in networks of actors/actants. Latour describes the networks by stating *"Behind the actors, others appear; behind one set of intentions there are others; between the (variable) goals and the (variable) desires, intermediate goals and implications proliferate, and they all demand to be taken into account"* [42, p. 100]. The social-technical focus draws attention to analyzing both the visible (the technical/objects) and the invisible (the social) and identifying the relationships between these. These relationships can be both material and semiotic simultaneously and combined into a network of actors that acts as a whole [43]. Tatnall and Gilding (2005) argue that ANT can be particularly useful for studies in areas that involve a consideration of some of the social and political issues in information systems. They further mention interface design, usability testing, and the use of distributed systems within organizations as examples of areas where ANT could be beneficial [44].

There is an increasing focus on how ANT could be fruitful in a design of information systems [14], [45], [46]. Stuedahl and Smørdal found that *"involving ANT concepts in co-design does help to frame co-design processes within the wider context and consequences of emerging knowledge development"* [47, p. 204]. Others, focused on ANT in relation to designing visualizations that makes things public,

in order to interest and engage people in participatory processes [48]. Storni explored how ANT can be used to offer an alternative perspective to co-designers, focusing on *"a convention from Latour's call for risky descriptions to a call to design things together"* [14, p.167]. He further argues that ANT suggests three general turns to rethinking co-design and participatory design practices. The first turn addresses the question of *what* to design? It also involves the idea to first *design actor networks,* and then look for ways to map them. He further describes the resulting maps as not only descriptive, but also as supporting participation in the design process. The second turn concerns the question of how to co-design and suggests the idea of designing as actor-networking (in public). The last turn, described as epistemological, involves what Storni describes as *"moving from the idea of the designer as a network prince to the idea of the designer as an agnostic Prometheus"* [14, p. 167].

III. ME/CFS AND DESIGN OF TECHNOLOGY SESSION

As mentioned in the introduction, this study uses a combination of user research, literature review and analysis inspired by ANT and Giga-mapping in order to tease out real problems and design opportunities related to assistive technologies for young people with ME/CFS.

In terms of user research, we have organized a sense-making session with experts on ME/CFS. These experts have a deep knowledge of ME/CFS. They have daily contact with children, youth and adults with ME, as well as their families, and therefore have a broad, personal knowledge of ME and experiences with ME challenges in lives of the sufferers and their families. These people came from 1) the Norwegian ME organization [18], 2) an organization that provides support to families of ME/CFS sufferers, 3) ME/CFS youth organization and 4) a medical doctor. The session lasted for close to three hours. The first part of the meeting was dedicated to getting to know what these organizations do. The results of insights gained are incorporated in Fig. 2.

The second half of the session was used to discuss future technologies that could be useful for ME sufferers. Given the aforementioned deep insight available within the group, many design opportunities for future technologies, as well as novel uses of existing technology, were considered. Some of the suggestions that do not exist today, and are viewed as helpful, are presented bellow.

The first suggestion was related to education, an important area for adolescents. It was an online e-learning solution with streamed lectures, accessible any time. It was brought up that most young people with ME/CFS want to follow up on their studies, but they have to be able to take a break when needed. This addresses the need for a flexible educational system.

The second suggestion was an App designed with a critical design approach with special focus on how the energy levels are different for people with ME/CFS. The App could simulate the amount of energy needed for simple everyday tasks in order to reduce prejudice and increase general understanding of the disease.

The third suggestion was another App that could be designed for self-management of the disease. The App could

provide reminders to rest. It could also give short advice on things that have worked for others, which they could try to reduce illness symptoms. The App could also measure sound levels and give warnings when the levels are too high. Since exposure to high sound levels is known to increase illness symptoms, the App could also help visualize this, by showing sound measurements and giving reminders to use earplugs in spaces with high sound levels, e.g., when using public transportation. General personalized everyday reminders were also seen as valuable, as increase in disease symptoms may lead to memory problems and forgetfulness.

The fourth suggestion was an electronic diary that could be used to register symptoms daily. The knowledge and awareness gained through daily activities, and their effects on illness symptoms were seen as valuable. This diary could also be a tool to explain better the current health status to healthcare professionals and social workers. For this diary to be used in periods with increased illness symptoms, it would be of outmost importance that the self-rating process is easy to conduct.

The fifth suggestion was related to wearable devices, such as the Fitbit. ME/CFS sufferers experienced the possibility of tracking activity, sleep patterns and energy expenditure as desirable. It was suggested that a similar wearable technologies, tailored to the needs of people with ME/CFS, could be valuable.

The sixth suggestion is a Social technology specially designed for people with ME/CFS, to meet and seek support from other people with the illness.

The last one considered novel discussion platforms.

IV. ADOLESCENTS WITH ME AND ANT

Instead of considering any one of mentioned suggestions as a design opportunity, and in isolation, we performed a broad analysis, focusing on all data collected from the sense-making session with experts. At first, the traditional ANT analysis was used, but then, a more pragmatic, design and technology oriented approach was taken, in line with the literature such as [13] and [46]. The result is shown in Fig. 2. The image is a visual representation, a Giga-map at the macro level. All the relations shown are significant for the initial sense-making process. Each relation explicitly or implicitly contributes to discussion around technology that could aid adolescents suffering from ME/CFS in some way. Three large connected areas of the network emerge, related to what we named Personal/family, Educational and Governmental design spaces. At present, these spaces are not strongly connected, and connections within each one of them are sparse. As mentioned earlier, also in the literature, there were very few results to mention.

In Fig. 2, a circle represents an actor and lines represent relations between actors. The number of actors shown is limited to the actors identified in the data analysis from the sense-making session with experts on ME/CFS. Actors in the network are both human (such as the ME/CFS sufferer, family members, hospital doctors and school teachers) and non-human (such as politics, prejudice, economics, and social media). They all have a role in and influence on the network. These roles and influences are not predefined but continuously evolve. For example, a family member may consider himself or herself to be without prejudice in other situations, but in the network representing the youth with ME/CFS they still can think that the adolescent is lazy rather than sick, and so contribute to maintaining the prejudice around the disease.

Adolescents, different people that they interact with, as well as non-human entities, obviously form different heterogeneous networks. This directly relates to the wickedness of problems related to defining technologies that aim to help youth to have a better life, given their condition. Not only adolescents suffer from the condition to varying degrees, but their condition changes from day to day and period-wise as well. This changeability needs to be addressed as part of the sense-making.

Furthermore, the analysis revealed two mediators. Mediators are non-human entities that increase difference among actors and, thus, should be carefully studied [49]. Mediators that we have identified impact how our society currently meets ME/CFS sufferers. Referring to Fig. 2, and the actors (human and non-human) in the network, the two mediators are marked with red circles. They are *Understanding of ME/CFS* and *Prejudice*. The first one is seen as a contributing factor that defines relations between ME/CFS sufferers and many other actors in the network. It influences, for example, how the social service caseworkers or physicians handle youth with ME/CFS. The *Prejudice* seeks to impose its version of reality on ME/CFS sufferers. *Prejudice* may determine what people see and in turn how they act towards people suffering from ME/CFS. As one person from our expert session said *"If one could only eliminate the burden of the shame that many people with ME/CFS live with, and shift the focus to acceptance and to living their lives as best as possible, the quality of their lives would be so much better."* The red edges drawn in Fig. 2 between the *Understanding of ME/CFS* and other nodes are also relevant for *Prejudice* as an actor in the network. However, the two are co-dependent: as the knowledge about, and understanding of, the ME/CFS increase, prejudice decreases.

Other concepts from ANT, such as agency and delegation, are also very relevant but will not be further described here.

V. CONCLUSION

The numerous challenges related to ME/CFS are not easy to solve and clearly relate to the main characteristics of wicked problems. We have proposed a holistic approach to sense-making when considering technology design for adolescents with ME/CFS. Using a literature review, a sense-making session with experts, ANT and Giga-mapping, we gained insight in what ME/CFS is, developed the empathy with youth suffering from it. ANT provided rich descriptions of the complex design context and Giga-mapping visual representations of relations that emerged as relevant. They also helped to define possible areas of interest for design (Personal/family, Educational and Governmental). Our findings align well with the literature related to Personal/family and Educational space. Another

possible design focus could be relate to the mediators found - understanding of ME/CFS and helping to reduce prejudice and stigmatization through design.

All relations among actors are significant for the initial sense-making process. They all, explicitly or implicitly, contribute to discussion around technology that could aid adolescents suffering from ME/CFS. Jointly, they provide a tool for critical reflection in the early sense-making phase of trying to understand adolescents with ME, and the situated design space related to technology that could be useful in their lives.

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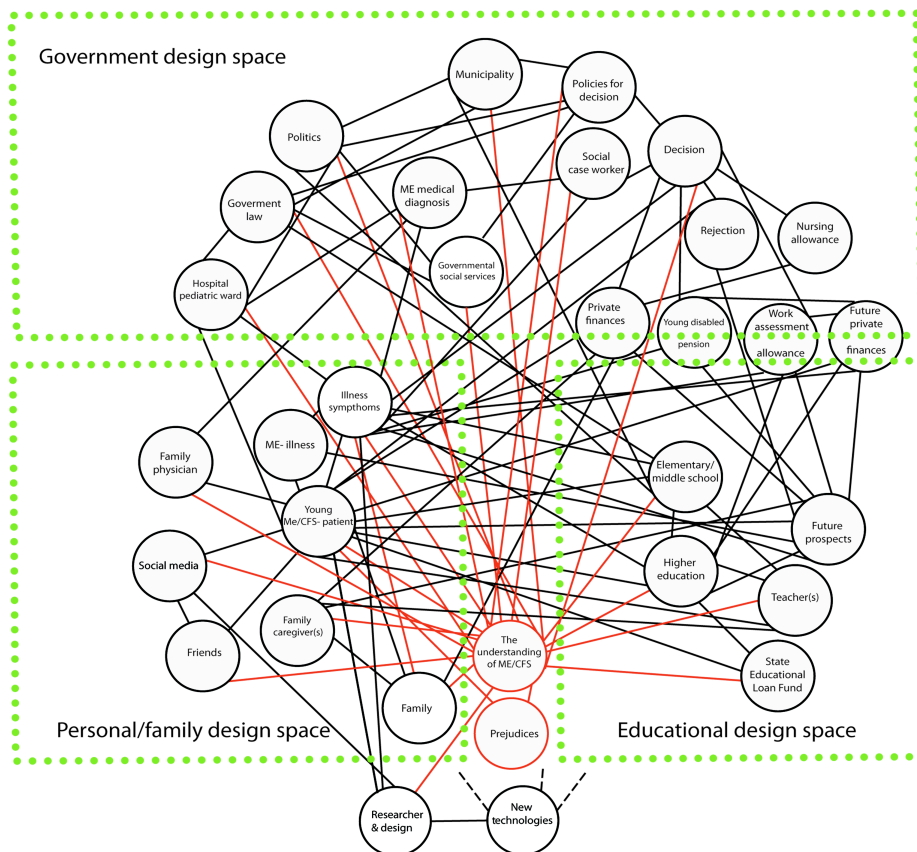
Figure 2.   Using a combination of Giga-mapping and ANT to map out design spaces and consider design opportunities.