Master's thesis

NTNU
Norwegian University of Science and Technology
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Department of Social Anthropology

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Welcome To The Syndrome-X Family

A song of knowledge and hope in a digital family group

Master's thesis in MSANT
Supervisor: Hans Martin Thomassen
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WELCOME TO THE SYNDROME-X FAMILY

A SONG OF KNOWLEDGE AND HOPE IN A DIGITAL FAMILY GROUP

Masteroppgave i sosialantropologi

Veileder: Hans Martin Thomassen

Mai 2022

Norges teknisk-naturvitenskapelige universitet Fakultet for samfunns- og utdanningsvitenskap
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For all the strong and wonderful Syndrome-X Family members, I am honored to be on this journey with you

For Asbjørn, Anne Lovise and Hailey Sophie

CONTENTS

SAMMENDRAG

Sosiale media har åpnet steder for tilknytning og samfunn hvor dette før ikke har vært en mulighet. Facebook-grupper for foreldre som har barn med sjeldne tilstander er eksempler på slike steder, og denne avhandlingen er basert på feltarbeid i en slik gruppe: *The Syndrome-X Family.* Ansett som en ultra-sjelden tilstand, med mindre en et hundre kjente tilfeller på verdensbasis, er Syndrome-X som regel ukjent for både foreldre og medisinske profesjonelle, noe som etterlater familiene i usikkerhet, i møte med det ukjente. Syndrome-X familier er geografisk spredt over to kontinenter, men gjennom digital teknologi har de nå kunnet kommet sammen og delt sine erfaringer, utveksle kunnskap, og se mulighetene i livet sammen i en utvidet digital familie.

Denne avhandlingen er en antropologisk utforskning av denne digitale familien, med spesiell oppmerksomhet til konseptene og prosessene av kunnskap og håp. Ved å følge I fotsporene til Fredrik Barth, søker jeg å identifisere de fremtredende prosessene av produksjon, reproduksjon og bruken av kunnskap som finner sted innad i familien, men også mellom familiene og det større kunnskapssystemet innenfor hvor Syndrome-X familiene befinner seg.

Etter inspirasjon av verkene til Hirokazu Miyazaki og Cheryl Mattingly, utforsker jeg hvordan kunnskapsprosessene for Syndrom-X familiene åpner opp for håp, og jeg argumenterer at håp i sin tur gir Syndrome-X kunnskap en positiv retning. Gjennom sin delte kunnskap finner de også fremgangsmåter til hvordan de kan forsøke å sørge for at barna får et godt liv, ikke et liv som handler kun om overlevelse, men et liv hvor de kan delta i samfunnet. Dette er deres håpsarbeid.

Prosessene av kunnskap og håp dukker opp i en distinkt temporal bane som kan bli identifisert fra å være en individuell familie til å være en del av den utvidede digitale familien, i steg fra å føde et barn med en ukjent tilstand, til å være foreldre som har mistet sitt barn.

Denne avhandlingen er basert på et fem måneders digitalt feltarbeid innad i The Syndrome-X Family, gjennom en tilnærming av digital etnografi.

ABSTRACT

Social media has opened spaces for connection and community where it has not been an option before. Facebook groups for parents of children with rare conditions are examples of such spaces, and this thesis is based on fieldwork in one such group: *The Syndrome-X Family*. Considered an ultra-rare condition, with less than one hundred cases worldwide, Syndrome-X is usually unknown to both parents and medical professionals, leaving the families in uncertainty, facing the unknown. Syndrome-X families are geographically scattered across two continents, but by digital technology they have now been able to come together and share their experiences, exchange knowledge, and see the possibilities of life together in one extended digital family.

This thesis is an anthropological exploration of this digital family, with special attention to the concepts and processes of knowledge and hope. Following in the footsteps of Fredrik Barth, I seek to identify the salient processes of production, reproduction and use of knowledge that take place, within the family group, but also between the families and the larger system of knowledge in which the Syndrome-X families find themselves.

Inspired by the works of Hirokazu Miyazaki and Cheryl Mattingly, I explore how processes of knowledge for the Syndrome-X families opens for hope, and I argue that hope in turn provides the Syndrome-X knowledge with positive direction. Through their shared knowledge, they also find ways in which they can make sure their children have a good life, a life not only about survival, but a life where they can partake in society. This is their work of hope.

The processes of knowledge and hope show up in a distinct temporal trajectory that can be identified from being individual families to becoming part of the extended digital family, in steps from giving birth to a child with an unknown condition, to being parents whose child have passed away. The thesis is based on a five-month digital fieldwork within the Syndrome-X Family group, approached trough digital ethnography.

ACKNOWLEDGEMENTS

I want to express my deepest gratitude to the Syndrome-X Family for their trust and kind participation in this research project. Thank you for being the guiding lights for each other, and for me.

I want to thank my supervisor Hans Martin Thomassen for nudging me in the right directions, while still allowing me to find my own voice and follow my own path during this project, and for reminding me that *through* is spelled with two h`s in it.

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Thank you to my fellow students, Vibeke Setten and Tuva Spigseth. Even though we all worked on our own individual projects, we got through these years together as a team. Thank you both for all the support, for us being each other's cheerleaders, for all the laughter and all the tears. It has been an honor walking this road with you.

Thank you to my dear friends Renate, Mari, and Lars for always believing in me, even when I did not believe in myself. Especially Renate, for cheering on me every step of the way, coming to my rescue when the process of writing about something so close to home proved to be too much, for always being there, and for babysitting, as watching mom write is not an exciting experience. I would not have pulled through without you.

Thank you to my mother for all help with the kids, for your support, and for listening to longer talks about anthropology, even though it is far from your fields of interest.

To my wonderful, patient, strong, wise, and brave daughters, I love you to the moon and back. Thank you for being so patient with your student mother. I hope I have shown you

that anything is possible if you put your mind to it and heart in it, I have learnt it from you. Thank you, girls, for being who you are. I am lucky that I get to be your mother.

Thank you, dad, for teaching me to think of the world and humanity in bigger ways than black and white, and for teaching me to see the world through anthropological eyes, long before I knew what anthropology was. And thank you for leaving me with the words “giving up is not in your dictionary.” I know you would have been so proud. I did it, Dad.

PROLOGUE: A Rare Insight

Imagine for a second, that you are a parent to a child who is born with a serious medical condition. Now imagine that this condition is so rare, that neither your doctors, nor anyone around you has ever heard of it. You have so many questions, concerns; things you need-, and want to know, and no one to ask. Maybe yours is the only child in your country with this condition. Who do you turn to for advice when you cannot even turn to medical expertise where you live? Where can you go? Where do you and your unique experiences belong?

Under one hundred children worldwide are known to the medical community with the diagnosis of Syndrome-X. Initially known as a childhood condition, having a bleak prognosis of 2-3 years, it is a serious condition, and it requires a massive amount of treatment and care, throughout life. For a family, this condition means living half of your lives in the hospital, and the rest at home with proper, often 24-hour care. The Syndrome-X parents have joined forces in an online support group on Facebook: The Syndrome-X Family.

Before you read on, you should be aware of this: All the names of the participants, including the name of the syndrome itself, have been given pseudonyms to protect the privacy of the participant families in this study. We will get to know members from both Europe and America, and their experiences of being a part of this family group. We will also touch upon sensitive subjects like bleak prognosis and death, themes that should be approached respectfully and with deep gratitude for those who have been willing to share their experiences in this study.

*

February 28th has come to be known as World Rare Disease Day. This day is a global movement seeking to raise awareness-, and advocate for equal access to healthcare and social equality for all who live with a rare condition. According to their website, a disease is rare when it affects 1 in 2000 people, however Syndrome-X is considered ultra-rare, meaning that it affects 1 in 50.000 people or less. [1] It is estimated that 300 million people worldwide live with a rare condition, and Syndrome -X makes up 1 of 6000 rare diseases known to the

[1] Information taken from: https://www.rarediseaseday.org/what-is-rare-disease-day/

medical community. In a universe of multiple rare conditions, Syndrome-X is its own little planet. Celebrating Rare Disease Day, Miranda, a mom, and a member of the Syndrome-X Family from USA, wrote this in a post in the Family Group:

> *[The Family Group is] …an ever-expanding global community of people who love a person with Syndrome-X, our Syndrome-X Family. I am grateful every day that we are not in this alone. Together, we are strong. - Miranda*

Welcome to the Syndrome-X Family.

1. INTRODUCTION

In this introduction, I will address my research objectives and placement, the chapter outline, and introduce you to the Syndrome-X Family. The introduction of the Syndrome-X Family is based on general information regarding who the members are and how they use the Family Group. I will also touch upon language and gender, before lifting the gaze to the context in which the Family Group is situated.

1.1 Research objectives and placement

Max Weber spoke of the role our own values play in directing scientific attention (Robbins, J, 2013). The choice of field and theme in an anthropological study is rooted in our own interest, our own values, and questions we have about the world around us. The inspiration of my chosen fieldwork, and subsequent thesis which you now have before you, came from a source close to home. Access to the Syndrome-X Family group is restricted to family members, and some others who either are caregivers for the children or employed by the foundation. They all have personal and/or professional ties to the group. The same goes for me. I am a family member. Originally, my intended fieldwork was to follow state licensed wolf hunters in Norway, but due to COVID-19 and kids, I had to change my focus. This group was in the back of my mind all along, although I was hesitant due to how personal this could get. But I knew it was a unique field with so many facets which could be explored trough an anthropological lens, plus – I wanted to take a different approach to rare-condition parenting, an approach which does not focus on suffering or marginalization.

I decided to "take the risk" and ask my fellow members how they felt about it. Lucky for me, they were positive. At the same time, I do not take the trust I was given lightly.

I knew right away that knowledge would be a good approach to this field: it is because of the *need* for knowledge that it exists to begin with.

This thesis is based on five months of ethnographic fieldwork within the Syndrome-X Family. With this position as a member and a researcher, I wanted to open the door into a life where most do not have access or insight– in society or in science.

My analytical interest sets its focus on how the Syndrome-X Family share knowledge, within-, and outside the Family Group, and how shared knowledge leads to processes of change and action. For example, how knowledge based on individual experience is transacted parent to parent, and from experience to expertise. I also want to explore how hope connects to sharing knowledge in rare-condition parenting, in the face of the unknown and uncertainty that comes with it. I will also argue that by applying the concept of knowledge-, and analytical approach thereafter, we can say something about how coming together in sharing experiences, we overcome the structural and cultural differences that often sees us set apart from one another.

This thesis will be a contribution to anthropological literature on online communities for parents of children with chronic illness, and the place of knowledge in rare-condition parenting, themes often seen under the heading of medical anthropology. This thesis also discusses hope, and common humanity based in the anthropology of the good.

These are the research questions I have asked of the field:

1. Is there a comprehensive process that happens from having a child with an ultra-rare condition to becoming a member of The Syndrome-X Family?
2. How is knowledge shared and acted upon, within-, and outside of the Family Group?
3. How is hope tied to knowledge, and how is hope "visible" in the social processes of knowledge-transactions (Barth, 2002: Aspen, 2001) for the members of the Syndrome-X Family?
4. What is the work of hope in the Syndrome-X knowledge tradition?

When you read the introduction of the Syndrome-X Family, you might ask yourself why I did not choose to approach this field with the focus being on the concepts of family and kinship. Although touched upon in family and familiarity, and the concepts having strong ties to the arguments made in this thesis, I chose to opt for knowledge and hope. The reason for this is simple: Family is an emic term, yet it means something quite different to every person in this group – it is a concept heavily influenced by cultural context, and up to subjective interpretation. Understanding the meaning of family in a way that is meaningful, both to the group members and to science, would still in my opinion necessitate the understanding of knowledge, its processes, and its resulting relationships as a foundation.

Also, one thing I deemed important for this study, was to have an approach that considered the individual experiences of people who too often become conceptually placed into collectives where their individual voices and experiences drown out. The anthropology of knowledge is an approach which sees contradiction, variation, and individual experiences as essential parts of knowledge traditions, as opposed to the diffuse sharing implied by the concept of culture (Barth, 2002; Aspen, 2001), and therefore their voices become essential parts of how I approach the knowledge tradition of Syndrome-X.

1.1 Chapter outline

This thesis consists of seven chapters.

Chapter 1 is an introduction of objectives and placements for research, chapter outline and an introduction of the Syndrome-X Family. In research objectives and placement, I state my inspiration for-, and intention of this thesis. I will formulate my aim and analytical focus trough research questions, and my motivations.

Chapter 2 gives an overview of the theoretical framework for this thesis, specifically knowledge and hope. It also discusses the ethical considerations of this study, my role as a researcher and a family member, and the methods chosen for fieldwork. Lastly, it gives a brief presentation of the field, and definitions and previous research.

Chapter 3 is the first empirical chapter, where I will introduce you to the participants whose stories and experiences are the backbone of this thesis. This introduction happens trough shifts in perceptions of time and possibilities, in a process of time, and over time; from having a child with medical challenges, trough diagnosis and prognosis, culminating in membership in the Syndrome-X Family. Trough this chapter, we see how these shifts in perceptions are tied to shifts in knowledge. We also look at acts of hope and hope in the suspense of waiting, from a dark time of prognosis to a place for hope.

Chapter four visits four different knowledge processes and "manifestations of concrete processes involving concrete persons" (Aspen, H, 2001, p.4). These are family and familiarity, sharing and comparing knowledge, the work of hope, and a shared journey. This chapter illuminates different individual experiences as they movie into a collective tradition of knowledge and shows how what can be experienced and compared is grounds for validity of knowledge. We will also see how hope is in the knowledge of the innate capabilities of the children, and how the work of hope is materializing knowledge.

Chapter five sees how knowledge, both individual and the collective body of knowledge in the family group, flows through the Syndrome-X knowledge system. It looks at how knowledge is tailored to different audience, based on the relationships between the sharer and those who receive. This is discussed with the theory of polymedia (Madinaou & Miller, 2012) in mind. The chapter also deals with how knowledge has its wellspring within the Syndrome-X Family based on the polyphonic collection of individual experience. How the definition of expertise shifts from medical professionals to experience expertise, as the Syndrome-X Family is the source of knowledge for professionals as well. Lastly, the chapter looks at experience of change, both technological and social in terms of being visible in society and having access to online communities such as the Syndrome-X Family group, and how it has impacted rare-condition parenting.

Chapter six explores changes in membership, presence, and sharing after a child has passed away. Through the process of sharing with the group that a child has passed to the balancing of sharing knowledge after, we see how the message of loss is conveyed, what considerations the parents make in sharing knowledge afterwards, and how membership not dissolves – but evolves, as it is an evolution in experience that takes place. It also touches upon the "material culture of absence," as the experience-based knowledge each child is the source of, and leaves behind, lives on in the Syndrome-X Family.

Chapter 7 is the conclusive chapter. A summary of what we have discussed, and following is the epilogue, which discusses what more there might be to explore.

1.3 Welcome to the Syndrome-X Family

In his book Ten Arguments for Deleting Your Social Media Accounts Right Now (2018), Jaron Lanier makes a persuasive case as to why and how social media is tearing humanity apart. Yet, he does acknowledge the fact that it has offered possibilities of connection where people have had a real need for it: "It`s hard to remember that people with rare medical conditions used to have no way of finding other people in the same boat, so there was no one to talk about unusual problems. What a blessing that it has become possible." (p.21). Even with all its perceived negatives, social media is at the same time recognized to be the place where people finally can come together and share their lives with others "in the same boat."

When a child becomes diagnosed with a rare condition, it is not just the child who becomes affected: it becomes a family matter. It requires extra work and attention on the part of the parents and caregivers, as information is not easily accessible or abundant. Belonging to a group of experts - other families with similar experiences, is of immense value. It helps in relieving the burden of researching treatments, having questions about development, and it is a space for visual evidence of how the condition plays out. It is a testimony to what is possible, and that there are others like your family out there.

There are approximately one hundred members in the Syndrome-X Family. Together, they represent eighteen different countries, spanning two continents, and multiple languages and backgrounds. There are parents whose child have just received the diagnosis, or that have gone for years without knowing there were others like them. There are also parents whose children have passed away.

Once you enter this family group, you enter a tradition of knowledge which is extensive. Fredrik Barth (2002) defined a knowledge tradition as *knowledge conventionally held*, which socializes its members in purposeful practice and relevance, and sees their individual experiences both shaped by it, - and their experiences in turn shaping the tradition. The thing that happens when someone becomes a member of the family group, is a shift in perception of time and possibilities. A shift from limited time to an open future of multiple possible outcomes. They get visual proof of children with this condition living to become youths, and even adults. Through the shared knowledge within the Family Group, they are presented with the variety of ways the syndrome will manifest itself medically and cognitively

in the children: seeing what might be expected of them as parents to navigate, now and in the future. In this group, they get access to information, and experience, which would not have been available to them before. This is valuable, not only in terms of support and co-experiencing the unknown of the syndrome, but it is also valuable for the medical teams that are responsible for the care and follow up of these children and their families.

The Syndrome-X Family is a place for looking at knowledge and hope, as they are a group of people that are in many ways dependent on each other's knowledge based on experience for navigating their own and seeing the possibilities life with this syndrome may offer. Of the approximately one hundred members, most of them are women. Moms. There are also sisters, and even a few nurses which have worked closely with the respective families over time. The men are fathers and brothers, and a grandfather. The women are the most active in terms of sharing and updating within the group, as the main representatives of each family. This raises some questions about sharing knowledge and gendered spaces, which will be touched upon in collaboration with the literature on support groups, - and how they are claimed to be constructed for feminine sharing, or female participation, in a question of gender suitability (Seale, C, 2006: Philips & Rees, 2017).

Some of the family members visit the digital family group daily, while others participate in specific situations - like seeking advice on a specific treatment that another family member has experience with. Family members use the group when they have specific questions relating to procedures, symptoms, and such. They are also active in commenting support, answers, and advice on what the other family members post on the group. There are family members that do not participate often in posting, commenting, and sharing within the group. Yet, this does not translate directly to them not participating in the family. Observing, learning, and employing the knowledge that circulates in the group, is a form of silent participation. Often, their participation shows up more explicitly in other ways: like communication and feedback with medical teams or raising awareness about the syndrome on other social media platforms.

The family group is closely related with the research foundation for Syndrome-X in Europe, which is small, and funded by the parents and other external donors. Founded by two family members, the foundation was intended to be the place to turn to for knowledge about the syndrome-, and for raising money for research by spreading awareness and finding donors.

Trough fundraising and working closely with one of the few medical experts on the syndrome, they have managed to fund research which is focused on finding the mutation

responsible for the syndrome, and to formulate standards of care for children with the diagnosis.

Every other year, the foundation arranges what they have called *the Family Meeting* in a specific location in Europe. The invitations and information about this meeting, also called the Family Weekend, is shared within the Family Group. Many family members have attended, some several times. They bring their children so they can see each other, and they can also bring siblings. Those who have not been able to attend plan to go when and if health, - and time allows it. Part of the funds collected by the foundation are meant for financing travel-costs for family members who want to attend, and a place to stay during the meeting. During the meeting, they get to meet the one doctor in the world who has specialized himself in Syndrome-X, and they discuss the latest research and treatments. In ways, this Family Meeting can come across as a hybrid between a family reunion and a medical convention. The information from the Family-Group on treatments and development is compiled based on discussion within the Family Group. This is presented to the families and medical professionals present. After the meeting, photos, videos, and information from the event is shared in the Family Group, and those who were present talk about how it was, and they share excitement for the next time they`ll see each other again.

The Syndrome-X foundation has its own website, which has compiled information about research on the syndrome, and has an overview of the children that have been diagnosed with the syndrome worldwide. Any research done has a process of recruitment where a representative from the foundation poses questions-, or recruits participants trough posts in the Family Group. These studies are always of a medical nature. On the foundation website there used to be a forum meant for the respective families to be able to connect and share knowledge. However, the forum was little known, and it has been described as difficult to navigate, and not very user friendly for those who have tried to use it. Therefore, one mom, Lisa from the US, decided to start the family group on Facebook, and all the other families quickly followed suit.

Language does play a role in how all members of the group can communicate with each other. I have divided language in this group into three categories: common language, native language, and medical language. The common language is English; it is the founding language of the group, most frequently used by its members. However, there are family members who communicate in their own native languages within the group, which makes translating a part of the communicative process. Especially French-, Spanish- and Brazilian members tend to write in their native languages. Medical language is common when

discussing treatment options, surgeries, or medical complications. Within the group, most have trough years of working with, - and having to learn the language of the medical professional community, adopted medical terminology and language for discussing symptoms, treatments, and procedures. Names of body parts and procedures commonly written in medical Latin or Greek. Together, common -, native-, and medical language make up the different layers of written-, and verbal communication within the Family Group.

Being a part of this digital family depends on two things: being a parent or caregiver for a child with Syndrome-X, and *access.* In this case, access is comprised of two essential elements: (1) access to technology which allows for the use of-, and presence on social media, and (2) access to health care of a quality that can a) treat the child, and b) give the right diagnosis. Genetic testing or international networks of medical information is not something available-, or accessible to every local clinic on the planet. We can only assume that there is a substantial "dark number" of families out there in the world which have an undiagnosed and/or untreated child with Syndrome-X. But it is likely that they are out there. Often, serendipity has played a key role in determining the diagnosis, and in turn, pointed the way to others, and the Syndrome-X Family.

In this thesis, I have looked at the Syndrome-X Family in several ways: as a family group, as an online community, as belonging to a tradition of knowledge and hence a part of a knowledge system-, and lastly, as a support group. I will quickly clarify the use of these different descriptions of them. They call themselves The Syndrome-X Family, hence it is the emic definition of who-, and what they are-; the way they define themselves. Community- or online community, is my analytical definition of the group. Rob Kozinets (2010) defined online communities as having both online and offline elements, and the concept community was referring to "a group of people who share social interaction, social ties, and a common interactional format, location or `space` "(cited in Pink, S et.al, 2016, p.106). The Syndrome-X Family "ticks all the boxes" in this definition.

A knowledge system refers to the constellation made up by the different spaces where the processes of Syndrome-X knowledge circulate - where knowledge is shared, acted on and understood as relevant and meaningful. The group itself are a part of it-, but it extends throughout multiple platforms used by the members, and medical communities, trough physical and non-physical spaces.

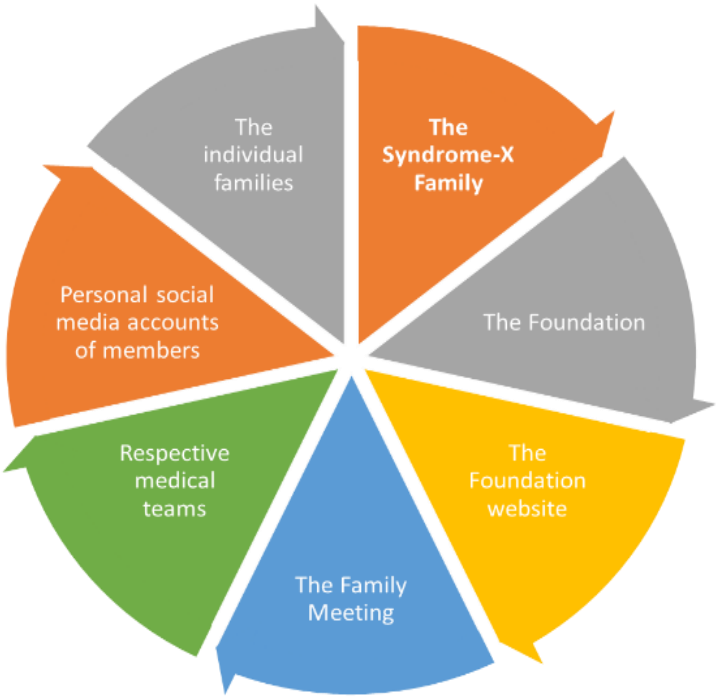

Figure 1 Syndrome-X System of knowledge

I have identified the Syndrome-X knowledge system as spanning these different spaces: the Family Group, the Syndrome-X research foundation, The Family Meeting, respective medical teams for each family, the research foundation website, personal social media accounts of family members, and the individual families' daily life. This is the context in which the group is situated, and knowledge circulates between the various parts of the system.

Lastly, the Syndrome-X Family was intended as a support group for the parents, and it is also defined as a support group by several family members and the research foundation.

There are members in the Family Group who have just joined, while others have been there since its conception in the late 2000s. As such, there are generations of members. This points to generations of knowledge-, knowledge passed on from those whose children are adults or passed away, to those who`ve just recently learned about the diagnose, and just embarked on their Syndrome-X journey.

2. TO STUDY A SONG

2.1 Knowledge

> "An understanding of the balances of sharing and difference in knowledge that predicate social cooperation should constitute a vital part of any theory of human society."
>
> (Barth, F, 2002, p.1-2)

When discussing an anthropology of knowledge, Fredrik Barth paints his terminologies as musical: using phrases such as "pitch," "register" and "harmony." Sharing knowledge is to sing -and dance to the same song. A song that blends different individual tones into a coherent melody. When the tones blend, they do not stand in oppositions to each other, but complement each other by moving in the same direction. Knowledge is a song unique to a specific way -, and view of life. It conveys a lifeworld through a harmony of individual experiences.

Contradictions and nuances have their place within an approach of knowledge, if they share some characteristics that make them relevant-, and meaningful for the tradition of knowledge in which they belong. Barth points to what he calls *harmonizing metaphors* (2002), which he links to: "… connecting known aspects of the world to shape an elusive, complex, and difficult-to-grasp appreciation of the pervasiveness and mystery of growth." (ibid. p.5). I argue that hope, journey, and experience are such metaphors, which trough a tradition of knowledge provides points of connecting individual experience to a collective, while keeping the uniqueness of each individual experience as valuable.

In his Sidney. W Mintz lecture in 2000, also based on his ethnographic material from New Guinea and Bali, Barth defined knowledge as "…what a person employs to interpret and act on the world" (2002, p.1), and that knowledge is distributed into formations, or *systems*, as opposed to culture which presupposes "diffuse sharing" (ibid.) According to Harald Aspen (2001), which employed Fredrik Barth`s stance on knowledge trough process and interaction, approached his field with knowledge as a theoretical perspective, looking at knowledge systems embodied in spirit possession in Mafud, Ethiopia. He describes the

anthropology of knowledge as “the inconsistencies within one culture” (p.13) Instead of culture as an abstract whole, the focus shifts towards systems of knowledge and social organization.

Knowledge is a living tradition which is produced and re-produced by individuals in a “in a process of transactions over knowledge” (Aspen, 2001). This processual stance is influenced by Barth`s process analysis: showing how processes of action and transaction, within contexts of stability and instability, leads to cultural and social change. This marks a shift from system perspective to an actor perspective, how the experiences and actions of each individual can lead to collective processes of action and change.

Applying knowledge in an anthropological perspective asks us to go beyond methodologically uncovering what knowledge is, and illuminate how it moves-, how it is shared and how it is used by those who are positioned within its circulation (Barth, F, 2002).Bronislaw Malinowski defined a system of knowledge as “coordinating action, standardizing techniques and imparting prescriptions for industrial, social and ritual behavior.” (Moore & Sanders. 2014, p. 99). In simpler terms, it is a system made up of norms and actions: there is a structure for sharing and acting, with a clear framework and borders. Knowledge travels through all parts that make up this system. For Syndrome-X we can think of a post that is shared in the family group containing specific information, which is shared throughout the other various parts, and so information, or knowledge, changes shape-, form and content throughout its journey.

As all the Syndrome- X Family members use social media to greater or lesser extent, how they make choices about what they share, how and where, can say something about this framework for sharing – not based on practicality, structure, or systemic factors alone, but as emotional and social acts. By approaching the use of different platforms and spaces where the Syndrome-X knowledge circulates, I argue that it resonates with Madianou & Miller`s (2013) theory of polymedia, which: “…shifts from the constraints imposed by each individual medium to an emphasis upon the social, emotional, and moral consequences of choosing between those different media” (p.169) Polymedia means the different types of media we have available to engage in social activities on, like different social media platforms. Madianou & Miller`s theory links the use of polymedia to how we relate to interpersonal relationships (ibid.). For example, things you share with a close friend can be different to what you would share with your sister, and the considerations of risk and possibilities tied to what you share -, and with who, translates to relationships built and set in digital spaces.

Developed in the light of migration and the increasing use of social media for maintaining relationships across distance, the theory of polymedia argues that:

"As the choice of medium acquires communicative intent, navigating the environment of polymedia becomes inextricably linked to the ways in which interpersonal relationships are experienced and managed. Polymedia is about a new relationship between the social and the technological, rather than merely a shift in the technology itself." (ibid. p. 169).

This also points to how navigating its environment is concerned with how knowledge is managed and experienced, trough social and emotional considerations.

When discussing analysis of knowledge in anthropology, Barth states that "our analysis becomes more illuminating if we are able to identify the *salient processes* of production, reproduction and use of knowledge that take place, and shape the forms of knowledge." (2002, p.6). These salient, or noticeable, processes can be identified by exploring how shifts in knowledge over time, from individual family members into the collective extended digital family, leads to new ways of understanding-, coping with-, and acting within a life with so much uncertainty and so many unknowns. One of these processes, is the process of hope.

2.2 Hope

> "The objects of hope and desire are always more than themselves. They are multimeaning symbols that have, in linguistic terms, enormous pragmatic force. They evoke a world, a society, a moral order, a psychology" (Vincent Crapanzano, 2003)

To capture how knowledge moves, how it is shared and acted upon, we must view it in an image which we can interpret and express. Michelle Obama, the former 1st Lady of The United States, once said in a speech: "History has shown us that courage can be contagious, and hope can take on a life of its own"[2]. When held collectively, hope can become something

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2 Remarks by The First Lady Michelle Obama during Keynote Address at Young African Women Leaders Forum. Regina Mundi Church. Soweto, South Africa. 2011

in and of itself, not extracted entirely from those who hope, but still elevated as a force of direction, - a movement that binds people together in a community of shared destiny. More than a temporal orientation, a positive thought or desire, it can also take shape as a way of being and interacting. I argue that in the case of the Syndrome-X Family, hope is not only an outlook on rare-condition parenting, but it is also a way of forming-, and being a part of the Syndrome-X Family and its knowledge tradition.

In his work The Method of Hope: Anthropology, Philosophy and Fijian knowledge (2004), Hirokazu Miyazaki shows how the Suvavou people of Fiji has a history of "thwarted hope". In 1882, they were placed in a village named Suvavou by French colonial powers. There were efforts made to preserve "… indigenous lands and customs" (p.31) by the government in their village. Oral tradition was taken as evidence based in collective knowledge that there was a monetary compensation set aside for them in exchange for the lands they were moved from, where the city of Suva is today.

"Over the past hundred years, however, Suvavou people have repeatedly demanded proper compensation from the government for the loss of their ancestral land, The government has repeatedly rejected these requests. Despite the government`s rejections, Suvavou people have continued to petition it […] they have deployed a variety of strategies in their petitions to the government and have searched for the exact place to `prick the taro leaf ` once and for all"

(ibid. p.32)

The imagery of the taro leaf – and by pricking it "in the right place," leading to a flow of compensation they know they are entitled to by oral tradition, is an illustration of *the work of hope* as making knowledge materialize. The work of uncovering, making visible to the outside what they know to be true within, lies in the acts of writing letters to the government, re-telling the story, and acting within this knowledge tradition in ways that are directed towards the materialization of the compensation. Ernest Bloch (1959) talks of hope as a "category of the not-yet/ forward-looking temporality". Miyazaki, however, shows how hope also is deeply rooted in the past, and therefore it is not simply a product of forward thinking. Hope evolves as a story of what was, what is and what is potentially to come- a story of the things we know and that we have yet to discover.

There are over fifty definitions on the concept of hope (Carotta et.al ,2017), but none that can rise above the subjective limitations of the concept to have it applied universally.

(Leite et.al ,2021). Aristotle defined hope as a waking dream. Leite et al (2021) defined it as "an inherent resource of human experience". It has also been defined as positive psychology and adaptation (Carotta et.al, 2017), a way to think and act towards future in the context of uncertainty and immobility (Kleist & Jansen , 2016), but the definition that catches my attention when looking at hope in the context of special needs parenting and caregiving, is Ernst Bloch`s definition:

"Hope is the pursuit of materializing the otherwise-than-actual" (1959)

Hope is often correlated with ideas of utopia (Bryant & Knight, 2019), but Bloch`s definition does not demand striving for a utopic future, and it does not imply that it must be strictly positive or rooted only in uncertainty. It does however open for hope as a way of striving for the realization of what we know to be true, just not yet visible. Hope, then, becomes more than a state of mind or a temporal orientation. In the Anthropology of The Future (2019), Bryant and Knight define hope as: "[…] a form of futural momentum, a way of pressing into the future that attempts to pull certain *potentialities into actuality*.". (p. 134). Hope becomes the act, or *work* of materializing knowledge and making potential visible– from implicit to explicit.

To analytically approach hope in his material, Miyazaki identified moments of hope, moments where the Suvavou people kept on trying different approaches to "prick the taro leaf," and the suspense in waiting for results. In what Miyazaki terms "indeterminate dualism" in knowledge, the people anticipate the fulfillment of hope as a confirmation of identity (2004, p.35). Waiting for this validation of knowledge is where "actors place agency in abeyance" (Abramson, A [2008] p.531). Abeyance, or in suspense, then, is where hope can take root. This shows how hope as an exemplary category of analysis can illuminate how our future goals, and perspectives on the here-and now, say something about how we view ourselves as individuals and collective groups, trough shared knowledge of who we *truly* are. This by having what is hoped for contain a promise of external confirmation of this knowledge.

Hope as a method, an analytical concept, has its place under the heading of Anthropology of the good. During the 1980s, anthropology experienced a reflexive shift from the "othering" of those we study, to what Joel Robbins (2013) refers to as the *suffering subject.* By the suffering subject is meant that the analytical focus of the researcher tends to

land on perspectives have negative connotations: marginalization, pain, oppression, poverty, and structural discrimination. Trauma as the embodiment of our shared humanity. (ibid.). Although this has served as a way out of the "othering" by identifying our "shared humanity beyond culture" (p.456), it has also played upon suffering and victimization. Robbins points to how a shift from such *suffering* concepts, to studying the likes of imagination, hope and empathy, can say something about the ways in which we perceive, and act on, sustainability in our daily lives. Sustainability in relationships, perspectives on time and ways of being. (ibid.) In other words, how we can find common ground in how we as human beings find, view, act upon and distribute the *good* of life. Parents of children with chronic disease have often been studied as "suffering subjects," and in public discourse in general. This thesis approaches them as "hopeful subjects," trough their shared song of hope and knowledge.

2.3 Ethical considerations

I have conducted fieldwork- and written this thesis in accordance with the ethical guidelines of NTNU, and the fieldwork and storage of empirical material has been done with the approval of NSD. I presented The Family Group with an information letter which informed them about the aims of this study. The letter was in English, but I also wrote information in Spanish and French. I pinned the letter in the group, so it was visible to everyone and easily accessible. They could give their consent in form of a private message to me, or a comment underneath the letter. I would also ask for oral consent before audio-recording interviews. The information letter also described what participation would mean for them, their rights as participants, and how their information and contribution would be stored in terms of privacy. All material containing privacy information was stored in encrypted files and was deleted after I was finished with sorting and analyzing the material. None of the participants has withdrawn their consent, and they have a positive stance towards this study.

Already before I started to write fieldnotes, I had made a list with an overview of all the members and given them pseudonyms. This list I saved on an encrypted memory pen. I quickly learnt the list by heart, so that all written material would only contain pseudonyms, and I could go to the list to double check that I was referring to the correct person. Risk analysis in this project was done continuously during my fieldwork and throughout analysis and writing.

As I conducted fieldwork in what can be perceived as a private space, containing medical information about third party people – children, I was careful to edit out any information not related to the informed and consenting participants, and anything that could lead to the identification of a specific child. The material from the fieldwork does not contain any information that is harmful, or information that can become cause for any conflict. As the majority of what is shared within the family group does concern the children, weeding out medical information and keeping the focus on the parental/ participant side of the material has been a challenge.

One does not simply join the Syndrome-X Family group. Access is restricted by its administrators who are also members of the family group, to allow only family members of children with Syndrome-X, known caregivers or representatives from the Syndrome-X Foundation to enter. My access, and knowledge about the existence of this group, is based on my own membership in it.

Throughout this thesis, consenting family members of this group have through their kind participation in this research project told their stories of belonging to this group, and about life with Syndrome-X. I have no intention of falling into the trap of making this thesis an "author saturated text" (Geertz ,1988; cited in Anderson ,2006), meaning that it becomes a story about my experiences where others are used as illustrations. Still, me being a member does have implications for the whole study: access, trust, ethics, and method.

Although the Syndrome-X Family knows who I am, and me being a fellow member, it does not directly translate to complete trust. It can also serve as a hinderance for sharing, as there can be a heightened sense of risk in sharing with someone who belongs to your group, and who will continue to be a part of it after the study. I had this in mind from the beginning, so I made the information letter I presented in the group detailed by explaining what anthropology is, what the aim of the study was, and how empirical material would be stored. Participation was strictly voluntary, and if anyone felt uncomfortable with the study, or wanted me to exclude them, they could just say the word. I have approached this with care, as to protect the integrity of my research as well as my role as a fellow member. The no-harm principle has been at the core of my approach. Throughout interviews and other forms of participation, I have reminded the participants about their rights, and the importance of sharing what they are comfortable with sharing. I have also made explicit their right to see the transcripts, take back parts or whole bodies of information they have shared, and I have held an open line of communication. They could contact me via e-mail and trough Facebook if they had any questions, concerns, or thoughts about the study. Regarding transparency and

trust, I also made available the contact info to NSD, and the Institute of Social Anthropology at NTNU.

In medical anthropology, auto-ethnography is common. Robert Murphy wrote about his own experience of paralysis in his work The Body Silent (1987), D.A. B Murray wrote about an HIV support group in which he himself belonged to in Positively Me (2020). The *reflexive turn* in social sciences in the 1980s opened for "[…] a heightened self-reflexivity in ethnographic research." (Anderson, L, 2006), meaning a more personal approach to anthropology and ethnographic fieldwork. We were to start looking at ourselves *in* the field as well as a part of it, and how it affects and changes us as well as those we study.

Autoethnography has several definitions, such as "[…] a form of self-narrative that places the self within a social context." (Butz, D; Besio, K ,2009), and "[…] researchers personal experience as primary data. (Moors, A [2017]p.387). However, Moors critiques the term auto-ethnography as to broad, as a researcher's personal experiences can be argued to be everything from his or her own background to fieldnotes and participant observation, making every ethnographic study auto-ethnographic. This thesis is not an auto-ethnography in line with these criticized definitions. It can, for the sake of argument however, be defined as an analytical auto-ethnography, insofar as it fills the criteria set by sociologist Leon Anderson`s (2006) definition of it: "[analytic autoethnography] refers to research in which the researcher is (1) a full member in the research group or setting, (2) visible as such a member in published texts, and (3) committed to developing theoretical understandings of broader social phenomenon." (p. 373). This definition describes my position in the field and my approach to it, and points to how it is not a study based *on* my own my experiences-, of my own experiences, but a study made possible to conduct *by* them.

My personal membership in the group has made me reflect on how the group works, and how it impacts us many times. But, entering the group as an anthropologist, with a set of methodological approaches and a quest-like mode of thought, I have gained new insights about this digital family, and my own life as well. There have been many times during the writing of this thesis, that I have deeply regretted the choice of doing research "at home." Especially, conversations about death and just taking in all the stories I have been privileged to listen to, has made it a challenge at times to sit down and write about them from a scientific perspective. I have been careful in terms how I have approached these stories in my analysis, and I hope I have done them justice and shown them the respect they deserve.

I have learned much about how anthropology and ethnographic fieldwork can affect a researcher on a personal level, and how to balance analytical distance and affective closeness

to the field. As this thesis is meant to be a journeyman test in research, I would call my study a real *ildprøve,* a Norwegian saying that directly translates to "a test of fire." It means that I chose a difficult path, and a rough, but hopefully effective way of growing my skills and understandings of what I am doing as a social scientist.

An important aspect of my dualistic role has been *reciprocal sharing*: meaning that I have during interviews shared my story honestly, as a reciprocal way of creating a basis for mutual understanding. When the participants shared their stories with me, they simultaneously shared knowledge and experience which resonates in our life, and so does our story to theirs. Still, this may also have its downsides. As I am a part of this family, participating in my study has become a dualistic experience for the participants as well. I assume what-, and how information has been shared with me through participation, while keeping the balance set by the framework of sharing from where we know each other, has been highly influential on my empirical material.

In this thesis, I prefer to use the terms *understandings* and empirical material instead of data. A wise professor of mine once pointed out that speaking of data collection when referring to information gathered through ethnographic fieldwork, and other social interactions, was making it sound like the data was something one could just go and pick. Like apples. Instead, the empirical material emerges from engaging with the research participants, a co-production of understandings.

On the last day of my fieldwork, I wrote on the group wall that I was now finishing and would now return to my role as strictly a fellow member, but still available for questions or concerns.

2.3 Method

The methods chosen for my fieldwork has been selected due to their relevance to anthropological research, to the field and to the frameworks of this study. While some methods were pre-selected, others were implemented during fieldwork as adaptations to the field.

Digital ethnography can give us new insights on phenomena such as trans-national relationships, globalization, and communication that cut across time and space. Doing fieldwork on digital platforms, however, can present some epistemological problems in terms of "real life" versus "virtual reality." When addressing the separation between technology and social life of physical presence in his social theory, Pierre Bourdieu states "… the distinction itself is a function of socially conditioned perceptions." (1984). I started this project with one of my main focuses on the separation of the digital and the real but understood that it had more to do with my perception of what a digital field site is.

In his book Coming of Age in Second Life (2008), Tom Boellstorff goes on an ethnographic adventure into a new world. This world has many different countries, cultures, and endless possibilities for creation. It is a world that, like our own, is constructed by its inhabitants and it continues to be produced and re-produced by them.

As he wrote: "[in virtual worlds] … selfhood, communities, even notions of human nature are being remade in them." (ibid.) Boellstorff defined his venture as an anthropologist that explores the virtually human, and inside this alternative reality he created a "support group" of sorts, where he did multiple interviews and recorded conversations. Tom ended up not only forming lifelong friendships and building a community in Second Life, but he showed trough creativity with his ethnographic method that online communities can indeed be methodologically approached in the same ways as physical ones. His work is an important contribution to ethnographic methodology, and how we approach research within digital contexts.

Inspired by the approach of Boellstorff, I decided to plan my fieldwork as if I was going to spend time in another physical space. The methods I decided to use were ethnographic approaches with some twists: participant observation, in-depth interviews, household survey, but also tailored to the digital context – exploring virtual spaces, reading written information, topic posts and so on, also understood as netnography. As in a physical

setting, netnographic method removes the "digital" as a determinant factor in and of itself, thus enabling me as a researcher to view the family group as I would any other social unit.

Netnography is a term developed by the sociologist Rob Kozinets (2010) as an approach for studying online communities. Online, space is not fragmented into small groups, each "hiding" behind their own closed links and own sets of algorithms. Like in all other parts of social life, everything is connected. Everything has a context, and netnography is an umbrella term for methods of exploring, analyzing, and interpreting the context of the digital social unit. Netnographic methods I have used for this study includes sampling posts and going through written texts, photos, videos, and websites related to the group, - as well as consenting participants other social media accounts and personal profiles.

I looked at how communication took place between members, including language, use of symbols for affective purposes like emojis, likes and shares, and what-, and how shared knowledge changes trough different digital spaces. What is shared tends to change based on *where* it is shared, and therefore this method is important: it can uncover the dynamics of sharing, and what is not being shared within the group itself.

Participant-observation in this study meant that I was present in the group as much as possible. Due to the lack of physical restrictions, and my privilege of access through both computer and smartphone, I had the unique opportunity to be "in-field" for as long as I could. I also had the possibility of leaving the field at any given time by simply closing the screen as a form of "stepping away" (Fletcher, 2019). This has enabled me to "catch" information from its inception, and to immerse myself in the field in another way than I would have by simply scrolling through the pages a couple of times a day. If I were to have based my "attendance" in the field by simply waiting for notifications, I would have missed a substantial amount of activity. Notifications only relate to activity which is related to you: like someone tagging you in a post, commenting on your content, or commenting within a confined space where you are active as well and/ or subscribe to the activity within that space. This means that when a member of the group posts something on their personal profiles or other social media accounts, or knowledge is shared on other peoples "online spaces," I would not be notified. Hence, being present in field as much as possible was necessary.

By not physically being in a community, in somebody`s home, place of worship or during routine everyday actions, I was not a factor of major disturbance in my participant`s lives in the ways I might have been, had I shown up in their homes. Eighteen different countries scattered over two continents would have been difficult to manage with a timespan of five months of fieldwork. Even so, the Syndrome-X Family itself is not scattered in

different physical spaces, but gathered in the family group online, so physical fieldwork in the respective countries would beg a separate set of research questions and direction of this thesis.

The downside of digital ethnography is that it can be problematic in terms of closeness and transparency between the participants and me. It might have led to a *contextual shrink*, meaning that the parts of their lives I have access to are somewhat isolated from their larger contexts: like how they live offline, and how they present themselves and share knowledge in other settings. In hindsight, I realize that I could have compensated more in terms of the contextual shrink by asking more specific questions around the participants everyday circumstances outside the group, things often taken for granted. It is a lesson I will bring with me in my future projects.

Video interviews done online was one of my main methods. I conducted the interviews via Zoom, an online video call service, which is free. Zoom was easy to use both for participants and myself, and there were no challenges as far as connection, sound or image were concerned.

When I interviewed Jane from Finland about what impact becoming a member of the family group has had on her, she replied: "… that`s not something I have really thought about a lot." Interviews can turn out to be conversations about things we usually take for granted, meaning it not only gives the researcher insight into the phenomenon she is studying, but also becomes a point of reflection for the one being interviewed. Because of this, and due to the sensitivity of the topics discussed, I always made sure to remind the participants about their rights to withdraw from the interview at any given time, no questions asked.

Participating in online activity is thought of as highly dynamic and flexible: available always for those with access, and it has no demand of your time in the same way as if you had to show up someplace in the physical world. Still, doing interviews and participating puts a demand on time, both on researcher and participants. In this study, demand on time is a multi-dimensional problem: firstly, it goes against the flexibility of being online: now the participant "has to" stay in place for at least one hour during an interview. Secondly, this is a group that consists of people who are caregivers of children with complex and high-level care needs, which means that time is precious and limited for the parents.

What separates a caregiver parent from "ordinary" parents, is that the caregiver parent give care far beyond what can be perceived as "expected childcare" in everyday life (Mattingly ,2010; Tiexieira et.al, 2019). This means that the question of time becomes extremely important when trying to schedule interviews. This was something I did anticipate

going into the field, so I knew that I had to get creative in how I would go about my fieldwork, because getting interviews would not be easy. I would have to supplement with empirical material from other methodological approaches.

The interviews were semi-structured, and my interview guide was quite simple, consisting of a few open questions like "How did you become a member of the family group" and «How has membership impacted your experience of Syndrome-X," and I would just keep going with follow up questions throughout the conversations.

Time-zones were a challenge. It took some work trying to coordinate time-zones so the members that participated in interviews had the time to sit down without being rushed, in a time of day for them where this was possible. With time differences up to six hours plus/minus, I found a time-zone map which made it easier for me to suggest times that would work for both participants and I. [3] This led to multiple late-night interviews on my part, and some early mornings for the participants.

I did *email interviews* where I sent a participant a set of open, but theme specific questions, and they could answer at their leisure. I also created something that I chose to call *topic posts*, where I would simply create a post with a topic, and open for a discussion off that topic for the participants to join in if, and when, they liked. I did a bit of *document research*, looking at the information available at the website of the foundation, and the existing literature on the syndrome itself. I did this to get a clear view of what is available knowledge for parents today, should their child become diagnosed with Syndrome-X. I also read news-articles and a biography related to Syndrome-X. This was all supplemented with a "household survey," where I made a survey consisting of ten short answer questions just to get a feel of some themes that would be a recurring.[4]

It was important to have respect for the fact that the members of this group must tell their stories many times over to new medical teams, and other parts of the network that constitute the total care of these families. Therefore, I kept things open ended so that they always shared what they felt like sharing, and I wanted to have it open enough to allow them to share about their personal experiences. I do think it was a great advantage for the field work that the research participants knew that I *knew*, as it made it easier to formulate experience without having to explain to me the basics of everything.

[3] The time-zone map I used: https://www.timeanddate.com/time/map/

[4] The questions dealt with online activity, general information about membership like duration and admittance, short descriptions of what the Family Group has meant to the individual members, and how membership has impacted their perception of life with Syndrome-X.

Language also had an impact. As previously mentioned, the main language for communication in this group is English, however there are members of the family group who write only in their native languages. I did not get zoom-interviews with them, but they did participate in topic posts and other discussions within the group itself. This might be because it is easier to get points across clearly via written text in the group, as it is easy to use translation tools. Hence, there is no awkwardness or difficulty in having a conversation in a language with which one is not comfortable.

2.4 About the field

Social media has become a large part of daily life for many people around the world: we use it as a site for connecting with friends, networking, keeping up with family, dating, promoting our businesses and so much more. Social media is also described as sites integrated into daily practice (boyd & Ellison, 2007). As social media is highly unrestricted by geographical borders as it is situated in a digital context, it has become a catalyst for globalization and trans-cultural connectivity. I choose in this thesis to use Daniel Miller`s et.al definition of social media as: "… the colonization of the space between traditional broadcast and private dyadic communication," and its effect can be seen as "providing people with a scale of group size and degree of privacy […] termed scalable sociality". (2016, p.9). By this we can say that social media is groupings of people located in between public media and personal relationships, diverse in size and culture, ranging from completely open to closed in terms of privacy and theme. In a way, it is a broadcasting of ourselves and our relationships – and we get to choose the audience.

There has already been written a fair share about how we use social media and how it impacts our everyday lives (Miller et.al [2016], Boellstroff [2008], Sterne [2003]). Still, social media is, like every space for social interaction, subject to development and change. This development and change are not only within technology and social media in terms of esthetic designs and function, but also our perceptions of previously thought to be fixed concepts, like relationships, kinship, identity, culture, and language. Social media, then, has been offering ways of re-defining concepts and categories we use to describe-, and understand ourselves and the world we live in.

According to Nicholl et. al (2017) “Nationally and internationally based Facebooks groups are now common for rare conditions. (p.2). There can also be down-sides to such an accessible and all-encompassing space of knowledge and support. It can cause unrealistic expectations on development and prognosis, and community dependency, where we can think of an online community as becoming an echo-chamber for a phenomenon, meaning that a perspective of “no-one else will understand” apart from the group can be adopted, and lead to a feeling of isolation in the physical daily life outside of the group (ibid.). It can also lead to challenges in comparison, in differences of developmental levels and medical complications between the individual member families.

On a smartphone or tablet, there are apps for the different social media platforms, and you can receive notifications in form of sound and vibration whenever there is activity like messages or a new post. Think of notifications as a nudge on your shoulder from someone that wants your attention. Several of the research participants answered on questions of activity in the survey, that notifications often dictate when they visit the group and when they are active on social media in general. If they have apps on their phones for Facebook, they are notified of activity in real-time, wherever they are. Fortunati (2002) describes mobile phones as: “[one of] the most intimate parts of everyday media” (cited in Pink, S et.al, 2016, p. 88). It is like carrying a community in your pocket.

What do people tend to share in such groups? The findings differ but shows that in groups that are meant for parents and caregivers, as our Syndrome-X Family, actual individual experiences and needs of the parent is often withheld, and the focus of sharing is more directed towards the children. The circumstance around them and concerns/celebrations of progress of that person. (Bitan et.al, 2018). Often, what is shared is also based on cultural preference; meaning and values connected to sharing and privacy. (Miller et.al, 2016). Such preferences can be identified by tracing information outside the group, and to see whether there are differences in what is being shared withing the group and outside of it. The group itself will have its own cultural preference, which is the framework for sharing and being a member.

2.4 Definitions and previous research

Tom Boellstorff (2008) contends that some scholars have critiqued using the term community when applied to digital social units, rendering them as "faceless communities that are less authentic and meaningful than actual-world sociality." (p.180). The question then begs, less meaningful and authentic to whom? There are distinctions made between so-called real life and virtual life, favoring the "real-life" as more authentic. "Real-life" requires social interaction within the same physical space – face-to-face contact, touch, smell, and sound. Yet, we can argue that social interaction within an online community also is a physical space as far as people can shape it, choose it and interact within it. Boellstorff (2008) writes:

"[What those who defend the use of the term community share] … is an appreciation for how community has never been reduced to locality: "that communities do not presuppose that member have to be spatially co-present or temporally simultaneous in their activities has been known for ages - already in the early civic public sphere in the late eighteenth century revolved not only around bourgeois salons but also around press and book publishing (Fornas et.al 2002:35)." (p.180)

The discussion of locality and community is important in scientific approaches to understandings of digital social worlds (Pink, S et.al, 2016). Manuel Castells (1996/1998) theory of the network society is a significant contribution to our approaches to digitally based social worlds, where he argues that "… fluid, transnational networks are the dominant social formations of our age, replacing earlier formations such as communities or associations" (ibid. p, 105). This is tied to the "global rise of networked individualism."

Wellman (2003) however, points to the concept of "personal communities" (ibid.), which are communities that are scattered geographically, but tied together in personal relations in virtual spaces that fall in line with the trend of "networked individualism" – personal networks. Rob Kozinets (2010) proposed a way of defining a community membership trough a continuum of participation, which involved: "… self-identification as a member, repeat contact, reciprocal familiarity, shared knowledge of some rituals and customs, some sense of obligation, and participation." (p.11)

When providing definitions for technology and a digital field site, as mine is, I have in mind what Jonathan Sterne (2003) proposes, that: "… our concepts of technology must be fashioned in response to the specificity of the practices we study." (p.384). As this thesis is based on field work in a closed, digital family group, and will be subject to analysis by such concepts as knowledge and hope, - I will define technology, digital field sites and online personal community as follows:

A. Digital field – places for communication and socialization which is non-physical and dependent on access to technology.

B. Technology – tools that allow for internet-based activity: specifically, computers, tablets, and smart phones.

C. Online personal community – social unit made up of consenting individuals, with set frameworks for shared content and themes. Of personal character tied in relationships of experience similarity. Situated in a digital field, and dependent on access to technology for existence and participation.

Digital support groups curated and managed by parents and caregivers, have found a way around the problem of lack of knowledge in the medical communities on ultra-rare conditions, and put the power of knowledge in the hands of those who live it instead of the medical professionals. This is shifting the definitions of expertise: how to get expertise, and who has the right to have it. In a combined qualitative and quantitative study of how parents of children with rare conditions use the internet, Nicholl et.al (2017) contended that: "… traditionally, health care professionals have been the gatekeepers of knowledge about the child`s rare condition. In some cases, the rareness of the child`s condition means that information is difficult to find, even for health care professionals, thus making diagnosis and management of the child […] and the condition difficult." (p.2) When a condition is no longer "text-book," the gatekeepers of knowledge become the ones who have the personal experience with the condition.

The intended function for the Syndrome-X Family group was to be a support group. Online support groups are also considered a part of e-health, which is "delivery of health information, for health professionals and health users, trough information and communication technologies." (Ahlin, T ,2013, p.7). This implies that health information, or knowledge, is equally accessible for both professionals and *users.* By information technologies is meant access to devices such as mobile phones and computers, which is described as "significantly

related to seeking health information […] specifically with the intention of identifying a medical condition for themselves or someone else." (Ibid, p.7). Later studies on e-health in medical anthropology have identified the need for investigation in online forums and support groups, and how health related information is spread, shared, and built upon (ibid.). This thesis will be a contribution to this, based on an approach of knowledge: how it is spread, shared, and built upon by the Syndrome-X Family.

An online support group has also been referred to as a "digital patient alliance" which has profoundly changed how people experience illness, shifting it from a private matter to a more collective experience (Phillips & Rees ,2017). Online support group differs from a physical support group in a myriad of ways: it is available 24/7, it is a space for open dialogue-, where in a physical support group there is usually a set time and topic for each meeting (Murray, D.A, 2020). It is usually not bound by geographical space, meaning that members can be from all over the world and still communicate in real time. While attending physical support group meetings means showing up, staying for a set time, and leaving, a digital support group provides the members freedom to come and go at leisure, withdrawing when it feels overwhelming and coming back whenever needed. Findings from such groups show that "patients engage in visibility work, actively trying to render their bodies visible and knowable to the clinical gaze" (Philips & Rees, 2017, p.215). I argue in that we can identify this *visibility work* in this thesis as the work of hope.

Most earlier research on support groups (Bitan, D.T et al, 2018; Fletcher, E.H, 2019 ; Murray, D.A. , 2020), and online groups for networks of patients and/or parents -caregivers (Coulson, N.S et.al, 2007; Høybye, M.T ,2016; Klarare, M et.al, 2020; Rafanell, I &Sawicka, M, 2019; Seale, C, 2006; Yuehua, Z et.al, 2019) has been conducted through the fields of psychology, social medicine and sociology. This also goes for specific groups for-/ of parents of children with disabilities and medical challenges (Solomon, M et.al, 2001; Teixeria, M et.al, 2020). Research on online support groups has looked at a wide range of topics, like gender suitability (Seale ,2006: Philips & Rees, 2017), how we form relationships (Miller ,2017), affective research presence online (Høybye ,2016), and member`s voice and agency (Yuehua ,2019).

Trough narrative -, and discourse analysis, Lawlor, Jacobs, and Mattingly (2010) approach African American mothers in special needs parenting, to see how they negotiate between individual experiences and being parts of a collective discourse. They also look at how resistance occurs towards the medical community from special-needs parents, as "clinical predictions impose constraints on the children." (ibid., p.5) In research done trough

what they dubbed “collective narrative meetings” with these mothers, a sort of research based support group, they argued that: “… women`s narratives reflect the complex work that caregivers do to make their visions shared visions and to compel greater appreciation for differences that typify their individual life experience.” (Ibid, p.5).

Even though a support group can be highly diverse, there are aspects involving the structures of sharing, and how they can be inhibiting for some members, or the whole group in terms of what is shared. For example, gendered hierarchies constitute a challenge which has been looked at regarding masculinity and femininity, and how support groups online are structured for sharing emotional content. (Rafanell & Sawicka ,2019: Seale ,2006). Clive Seale (2006) looked at a cancer support group, where he concluded that sharing in such groups points to “women`s culture” as in sharing emotional content, whereas men usually share more bio-medical information. However, Philips & Rees found that in a group of mostly women who shared the same, rare disease, the women shared bio-medical facts, and there was little in terms of emotional content and support (2017). This finding points to how the need for knowledge can have a foundational effect on what is shared and how. When something is rare, it is rarely known, thus such online spaces for sharing knowledge become important primarily as spaces for sharing knowledge about the shared condition. This finding resonates with the Syndrome-X Family.

In this chapter we have established the theoretical framework for this thesis, and discussed ethics and method, the field and definitions, and previous research. Now, to finally begin our Syndrome-X journey, we must go back in time – to when a child is born with medical challenges, but nobody knows what causes them.

3. PERCEPTIONS OF TIME AND POSSIBILITIES

"To formulate experiences of illness trough narrative is a way to understand life in time"
– Mattingly & Garro (1994, p.77)

How do you cope with the news that your child only has a few years at best to live, and how does this devastating message impact the experience of being a parent? Before the parents become aware of the group`s existence, or become members of it, reality of Syndrome-X is depicted as very bleak. It is the devastating moment of receiving the difficult knowledge of prognosis, or the feeling of isolation due to how rare Syndrome-X is. To explore such experience's trough the concepts and processes of knowledge and hope, is to see that *time* is of an essence. In this chapter, you will be introduced to the participants in this study trough their different experiences of diagnosis, prognosis and joining Syndrome-X Family group. Through this chapter, we follow changing perceptions of time and possibilities for the group members in shifts from not knowing, to hope connected based in knowledge.

3.1 A time to wait

During my first conversation on Zoom with Lisa, a family member from the United States, and coincidentally the founder of the family group on Facebook, I ask her how it was waiting for a diagnosis for her son. He was almost twenty years old when they first solved the puzzle of his complex medical challenges. After thinking about it for a few seconds, Lisa replied: *It`s lonely, I mean we were lonely you know? It was a hard wait up until we got this diagnosis.*

Due to early onset of medical challenges in children with Syndrome-X, particularly with breathing and nutrition, including very prominent physical characteristics, there usually is an awareness from birth that there is "something out of the ordinary" going on. To be diagnosed means finding answers to questions, treatments, and possible cures. Finding the right diagnosis, then, is an important quest, both for medical professionals and the families.

It often happens, that during pregnancy, a doctor can detect that something is “not quite right” on an ultrasound. There are tests to run, so the parents and doctors can figure out what to expect and for what to prepare. Syndrome-X can show up in an ultrasound, but as diffuse and small anomalies. There are no tests that can reveal it during the pregnancy, and as it is so little known, medical professionals do usually not consider it. All they can do is wait.

When the child is born there are medical challenges that usually become quite acute, and the parents and child wind up moving into newborn intensive care units. The doctors start doing detective work, trying to solve the puzzle the newborn child has presented to them. This sets in motion another time of waiting for the parents. Waiting for answers while trying to adapt to a very frightening situation, where their children’s lives are in danger, puts immense pressure on the new parents.

If the doctors manage to solve the puzzle, and have a geneticist confirm the diagnosis, the child – or more accurately the family, is diagnosed with Syndrome-X. However, the wait for diagnosis can last anything from weeks – to decades. The time before the diagnosis, then, is a time laden with uncertainty, unanswered questions, and no one else that share the same experience there to lead the way.

Jane is a petite, dark blonde woman with kind eyes, and she is also one of the youngest parents in the Family Group. When we meet in the Zoom-room I have opened, she greets me while her child is playing with what looks like Duplo in the other end of the room. When Jane`s son was diagnosed with Syndrome-X, Jane felt like the ground beneath her had been pulled away, and she had to face bonding with a child that she was going to lose. Jane's son was the only child in their country with this syndrome, which is common within the Syndrome-X Family. The amount of relief Jane describes in becoming a member of the support group she found difficult to formulate, as there was no one in their medical team or anyone else in their country that could answer the questions, concerns and fears she had about her son's condition.

Considering they were the only ones in their country, connecting with a community of others in the same situation was essential to learning about the syndrome. What treatments and tools were possible to try, what could be expected in terms of development and complications?

During the pregnancy, there were no indication that anything was out of the ordinary, so when their son was born, it came as quite a shock when he had to be rushed to intensive care. What followed was months of worrying, surviving, and waiting in suspense for answers. For Jane, the time waiting for a diagnosis was “*like standing in a dark room with no windows*

or walls." She recalls her husband asking the doctors every day when they could take their child home, but they had no answers for them. Because there was no diagnosis, they could not tell them whether their child was likely to survive or not. So, all they could do was wait. At the same time, in another country close by, Astrid`s child has come home from intensive care, yet without a diagnosis.

In a country in Northern Europe, Astrid is sitting in her living room in front of her computer, a cup of tea in her hand. She is blonde, and wears glasses. Her daughter is at her fathers for the weekend, so she is home alone. It is easier this way, it is hard to focus when you must keep your eyes, and mind, on your child all the time, *"…you know this*" she says. Our conversation runs smoothly, and it does not feel like an interview. She, her ex-husband, and her daughter, makes up one of four North European families in total who are known to have a child with Syndrome-X. When I ask her what she remembers from the time of birth and diagnosis, she replies:

Uhm… we had a child and she looked very different, and it was very difficult. So, then there were done some genetic investigations and a search began on what it was that could be wrong seeing that she had several medical issues and quite prominent characteristics.

It would take a year before they landed on Syndrome-X. Another diagnosis considered by the doctors, and as Astrid was searching on Google for information, she found a blog by another special needs mom. Her child had another diagnosis than the one Astrid was doing research on, but the similarities between the "blog mom`s" child and her own was striking. The medical issues the mom described in the blog were similar as well. She read that they had just received the diagnosis of Syndrome-X. Astrid said:

…. I could see that my child was identical to her child. So, I wrote her an e-mail saying; "My child looks like your child.", and after this we started having contact through e-mail and later on when our child was diagnosed it was like all the pieces of the puzzle landed in place.

The access to online search engines has led many to go on quests for answers in search for a diagnosis and options for treatments. You do not even need a name, just listing the different medical complications in the search box can be enough. In the face of an unknown condition, it might be all one can do. While some might find others by internet search, it has also happened when someone was not looking.

Lisa had logged on and entered the zoom-room I had opened. For her it was early in the morning, the sun was rising; in my living room it was late afternoon and dark outside. Here we were together, yet a world apart. As she appeared on my screen, she struck me at once as a warm and kind woman, in her early sixties, with a warm voice laden with a thick American accent. She was sitting in her cellar, as it was closest to the wi-fi, wearing a warm sweater with motives of bears and elk on it, and thick glasses. Her hair short, and silvery white. Seeing me on the little screen, she instantly waved, leaning forward while pushing her glasses up from her nose to her eyes as to see me better, and greeted me as someone she knew well. "Hi, so nice to finally see you!" she said. Lisa was ready to share, and she started to reflect over being a member of the Syndrome-X Family. I hardly had to ask questions at all during the interview.

For nearly two decades, Lisa has been living without knowing what was causing so many complex medical issues in her son, and without any one to really talk to about the unique things she was experiencing with him.

Yes, and I was desperately needing to talk to somebody because my son at that point was plus 19 years old, and we've been just in the dark for so long it was just like, whoa, see if you can talk to people yeah…. Before you did not get diagnosed early, or you passed away many years before you got the diagnosis

When I asked her about how she found out about Syndrome-X, Lisa gave me this description of how she made this *weird connection* to another Syndrome-X Family member before she knew her son`s diagnosis:

Um…anyway this is a little off the subject, but the weirdest connections, unusual, was that our local newspaper wanted to do an article about my child, and I shy away from stuff like that, I don`t want my child's face all over the internet, but uhm…. My husband thinks differently so we did a little piece and it was on local news and it was , videotaped and just a piece in the paper, and…uhm…the family of the oldest living person with Syndrome-X in another state, the brother picked up the newspaper on the internet, maybe he was just searching for Syndrome-X and that news piece came up [laughs]… and so , the mom called the TV-station and asked " Who are these people, I need to talk to them!", and they actually gave her my phone number [laughs] I couldn`t believe it! Anyway, she gave me a call, so that was … I mean we were friends 10 seconds into that conversation

While Lisa is one of those who went decades before diagnosis, Jane`s son was not a year before being diagnosed with Syndrome-X. During a stay at another hospital for a medical

procedure, a visiting doctor recognized features in Jane`s son from one of his other patients in his country. A case of right place at the right time.

Coincidences and serendipity bringing on the right conclusions, often thanks to own research rather than discoveries from their medical communities, is a common story in the Syndrome-X Family. The search for a diagnosis is a search for answers, and for a sense of control in the face of an uncontrollable situation. It can explain why different medical challenges occur, and better yet, there are usually specific treatments to be found, and others who share the same experiences. But it can also tell us something about time.

3.2 A dark time

It is not the receiving the diagnosis itself that hits like a punch in the gut for parents of children with Syndrome-X. When diagnosed, the information that truly sticks with them - the opening line of almost every story of a life with syndrome-X is *prognosis 2-3 years, a childhood condition.* Receiving the diagnosis has been for some likened to receiving a death sentence for their child. As Jane described the time after they finally received the diagnosis:

... I remember our time in NICU as a dark time. It was living day to day, and after finally being diagnosed and being informed of the prognosis, and doctors shrugging, saying "we don`t know". Do you think we can take him home? "We don`t know". Can he live longer than three years? "We don`t know" they said. So many unknowns, and the only partial "I know" we got was this prognosis. And that was something we did not want to know

Time, or the question of it, becomes of immediate concern. Time, when it comes to life, is often perceived as such: you are born, you live for a substantial number of years, and you die. In other words, time is something we often take for granted, a *doxa of temporality* (Bourdieu, P, 1977). Being born just to die within three years seems illogical, a miscalculation from the side of nature. It simply cannot be right. When confronted with this contradiction to what has been taken for granted, or *destabilization* of the concept of time (Mattingly, C, 2015), it can be difficult to maintain an outlook on the future which does not seem frightening. Future, in this way, can become synonymous with a movement towards loss.

Lisa in some ways considered herself lucky that her son was not diagnosed until so late. He was already grown up, and yet they were presented with medical information stating that he was not supposed to live longer than three years: *Wow, see yeah, I did not have to go through that! We found out when he was nineteen that he was only supposed to make it to*

three or four years old, I mean we just laughed and went "wow!", and I mean, there are still doctors telling that to parents and it just drives me crazy!

Lara from USA first found the Family Group when her daughter was in her thirties. She is a brown haired, petite woman with a big smile, and a big family. Her daughter was still an infant when they received the diagnosis of Syndrome-X. When asked about the time leading up to the diagnosis, Lara told me this story:

Basically, the diagnosis was not …given to us, it was sort of hidden. We read what we could, and our daughter… we went to another hospital because they wanted to speak to us and observe her for two days. We brought her there, because when she was two months, her original pediatrician said "yes there is something, but I don`t know", they were quite rude there, they did not want to put in the work of figuring out what was wrong…we took her to the geneticist, he said to me, if she was my child I would examine this further– let's do some x-rays just in case. It was a radiologist who found it out. We asked what it was…. this was in the 1970s, they said "oh, it is rare, she does not fit in to – not a classic case, there were only two other cases reported at the time. We had to do our own research; they were very vague. We had to find out on our own.

Obviously, Lara could not go on a computer and google it in the 1970s, hence they were spending time looking for medical literature.

Lara said that*: My brother-in-law found two articles, had them printed, and I read them and was horrified… the two original cases this was*. I instinctively know what articles Lara is referring to, it is the same articles that still pop up in searches in medical records, and online, four decades later. Lara, and those whose children are diagnosed with Syndrome-X today, have been exposed to the same dated knowledge, and to the same devastating news about how little time these children were to have on this earth.

Miranda is a woman in her thirties, and she lives in the middle of USA with her husband and children. A nurse by profession, she has experience with caring for other people in medical need, but caring that way for your own child is something different entirely. When he was two, Miranda`s son received the diagnosis of Syndrome-X. When posting about her son on Facebook in a fundraising post for his birthday, she wrote: *Raising a child with a rare disease means we don`t have answers to a lot of questions. It means we can`t know for sure what things will look like in 6 months, a year, 5 years, 10 years…you get it. There are a lot of unknowns.*

Miranda speaks from experience. Her son has been in and out of hospital many times the last couple of years, and there have been many close calls. Their whole family's life has turned upside-down, and they have been challenged to navigate the line between life and death, repeatedly. Their doctors did not know much about the condition due to how rare it was, and so they only had a few and very dated medical documents from which to draw knowledge. Searching databases of medical documents, this is the description they find:

"*The prognosis is poor, and most patients will die in the neonatal period or early infancy*."

Luckily, by conducting their own detective work online, searching for whatever information they could, they happened upon a mom who had her own YouTube- channel, a channel meant to raise awareness about her daughter's syndrome. Her daughter was six years old and thriving. Miranda reached out to her. The woman was Ivy, also a mom from US. She has several platforms that she uses to share various kinds of content. Her main goal with her YouTube channel is to give people insight into life with Syndrome-X, and hopefully, reach others who have yet to receive the correct diagnosis, or are living with it without knowing about the others.

There are others.

Apart from prognosis, the other major thing that happens in the moment of diagnosis, or when the child remains undiagnosed, is the sense of loneliness and isolation due to the unknown, and how rare the syndrome is. In a way, there is no-one to *hope* with.

Michelle is a woman with a warm smile and eyes full of wisdom. She is in her fifties and lives in the UK. She is an active member on the group, and someone the members look up to. Her son passed away when he was in his late teens. Michelle had been a member of the family group for a couple of years when it happened. After his passing she has continued her role as a family member, a person who supports and shares important knowledge. In one of our conversations, she recounted what it was like back when her son received the diagnosis of Syndrome-X. Her son got the diagnosis shortly after birth. Giving birth to him in another European country in the early 1990s, Michelle and her husband tried finding other families, but with no luck. The only one their doctor knew of was a family in a neighbor country, and that child had passed away as an infant. Michelle said: *Obviously, at the time, we did not think our son was going to live for long, so sadly we made the decision not to meet the family*

This reminded me of something Jane recounted that was similar to Michelle`s experience:

When the diagnosis was given, and before we were referred to the international foundation and the Family Group, our doctors had managed to find one family who had a child with this condition. They had the child in the early nineties, but she passed away at three. Both her parents were doctors. I thought that… you know, wow…if both her parents were doctors and they still could not save their child, that means there is no hope for us. So, when they asked me if I wanted to contact them, I decided not to.

It seemed that both for Michelle and Jane, the only ones they could talk to who had experienced having a child with this syndrome, had lost their children. Without knowing that there existed several families with other stories out there, it created feelings of isolation and fear for them. To deal with this, none of them gave up searching for others, the need for finding a community was strong. Michelle and her family moved to the UK, and there, during a continual search for others, a mother in the USA had heard word about Michelle`s family trough a doctor and made contact. There was someone out there.

Some years later, a nurse of Michelle`s son was searching for more information on Syndrome-X and came across this international research foundation located in Europe. Michelle contacted them immediately. She said: *We leapt at the idea of being a part of it, and I made contact and the rest is history. We were directed to the now famous family group. It was a relief. We just didn`t want to be out there in the world alone.*

3.3 A time and place for hope

As you recall from a time of diagnosis, Jane and Michelle decided not to contact the ones their doctors had found, as their child had passed. However, when contacted by the foundation and directed to the family group, Jane`s whole perception of Syndrome-X changed:

You have a community, you have someone to ask, and someone to compare experiences with, and at the same time… I mean, it`s a place that …it`s a place for hope, because you get to watch and follow all these other kids grow into teenagers, or into adulthood even, and it just proves you every day that your original fears were wrong, thank God.

There are several family members that have gone decades before having a group of other Syndrome-X families to turn to. Lara is one of them. Many of the other members mention her when talking about the impact of finding the family, as she also is the mother of the oldest living person with Syndrome-X. Looking at them, how they thrive and are living

this full, rich life, has been an inspiration to all the other parents. Lara did not have a family group to turn to and ask questions. Having her daughter in the 1970s, long before social media and online support groups – long before even knowing of others with the same diagnosis, it was a contrast to becoming a member of the family group and experiencing a community of people in the "same boat" as herself.

It was the serendipitous discovery of the other mom by online search that Astrid was directed to the Family Group, where the "blog mom" was already a member. When I asked Astrid what her experience of becoming a member of the Syndrome-X family was, she replied:

Well, it is getting more life isn`t it? God yes…when our child was born she was, like all our children, living in the neonatal ward for a longer period of time, with that I know that we were searching for other neonatal parents when she was a baby, or other children with disabilities and similar situations, but it was like getting life back, because you get in this group and you see that there is a future for our children, because you have such anxiety of death when you receive the message of the diagnose, uhm… so when you see kids who are teenagers, young adults, yeah… it feels wonderful.

The sudden shift from low life expectancy and the meaning of future as counting days, to suddenly having the opportunity to envision a whole lifetime, in other words, life beyond infancy and early childhood, is a major process of hope. The time thought to be lost after the diagnosis – and following prognosis, is in a way given back to the parents who become members of the family group. The group was founded not many years after Facebook was established and had become international. It all began with Lisa not really "getting the hang" of an online forum.

Lisa wanted to reach out to the other families after becoming aware of the international foundation. After trying for a period of two years to get the hang of the online forum the foundation had established, Lisa decided to try creating a Facebook group instead. She had not been keen on the "*whole social media thing*," but after consulting with some friends, she figured out it was worth a try.

> *[discussing the family forum on the foundation website] … yeah 50 emails in a day and we'd have to hunt around you know to find their messages, and I thought… I wonder if we could do this on Facebook, so I… it wasn't easy but I got myself added to Facebook and two families joined and then I got ahold of Martha [another member of the Family Group] and other ones …she was sort of the family coordinator you know*

for the international group, I said well we started this Facebook group of people, you wanna add in, let us know… so she is the one who referred everybody over you know to the Facebook page yeah

Maj: Yes, so you are the original founder then?

Lisa: yes, yeah yeah!

Relief, evidence, hope. These are words often used when describing how it felt finding- and joining the Family Group. Izobel, also from USA, is one of the newest members of the Syndrome-X Family, and she has raised her son on her own. In one of my posts where I try to recruit participants for interviews, Izobel is one of the first to volunteer. I e-mail her the details and we set a time. When I open the zoom-call, it`s late at night for her, and early in the morning for me. She is at home, her child in a wheelchair behind her. She is a woman in her mid-thirties, with shoulder length brown hair, and a big smile. *Hi, oh my gosh, this is so weird,* she says while laughing nervously. It is weird to see each other "live," as we have only ever seen photos of each other and our children in the Family Group. As we talk, we find common ground in many similar experiences: both single parents, both getting our master's degree. There`s a lot of "girl power" in the air. Izobel was clear that the shift from her son trying to survive, to suddenly seeing children that have not only survived early childhood, but thrived when entering the Family Group, has had a massive impact on her and how she views life with Syndrome-X. For her sons` first day of school, she wrote this in the Syndrome-X Family group:

I can`t believe that four years ago my child was fighting for his life in intensive care at just a few months old. We read about syndrome-x and were told about the three-year life expectancy and didn`t want to believe it. We feel so lucky to have met you all in this group and some of you in person, as your children have all taught us to ignore that life expectancy and reach for the stars.

The importance of finding others and belonging to a place where the perceptions of time and possibilities shift in a positive direction, is hardly difficult to imagine. When I asked Lara about experience of "being on their own" prior to membership, she gave another outlook on the matter, both yes and no. She told me: *It was very lonely before meeting the others,* at one point in our conversation, but at another point she replied:

[About the prognosis] … I could not have believed in that… I had to have a mindset to move forward, be positive and do whatever I could to give my child the best life possible. I am a real social person, we went out there, we did things….so no it was never lonely at all.

Lara illustrates with this how the loneliness, or isolation, is not necessarily due to lack of people around or emotional support, but due to the lack of others who share in their unique experience, a loneliness of knowledge. As Lara`s family went for several decades before meeting other Syndrome-X families, she had forged her own path on the Syndrome-X journey. But still, becoming a member of the group meant being able to participate, finally, in a community of families who shared their unique experience.

A geneticist coming to see another patient only to recognize the features of the child with Syndrome-X, to finding a blog after hours and hours of online searching or stumbling across that news piece. No matter the way in, when the diagnosis is given and they get that invitation to join the group, the individual families become members of the Syndrome- X family. After a time of waiting for diagnosis, for finding a community of people who share the experience, being directed to the Family-Group and seeing photos, hearing stories, and sharing knowledge marks a substantial change in how life with Syndrome-X is perceived. It is as if all the *closed doors and windows* Jane spoke of are opened – to new perceptions of time and possibilities.

As mentioned, receiving the diagnosis of Syndrome-X is not easy, and while some receive it shortly after birth or within the first year, others have gone several decades undiagnosed. This points to how the experience of the journey towards the Syndrome-X Family in terms of changed perception of time, differs greatly. The discrepancy in the newest and ever-growing information existing online contra the medical records is extensive. This constitutes the big leap from diagnosis to group membership in terms of perceptions of how *much* time a child has, and what possibilities lie ahead, if the child is diagnosed early in life.

In her study on cancer patients and treatment in Cuba, Naomi Schoenfield (2021) discusses how the term *cronicidad*, directly translated to chronicity, has been deliberately used of patients with terminal cancer by the Cuban oncological community. In this way, the patients become categorized into a larger societal group, where the chronic aspect suggests integration into "normal society" (p.5), and a shift from dying of, to *living with* the condition. She underscores this by using the concept of *charismatic time*, which is unbound by economic and direct temporal constraints, meaning there is a defiance of perceived boundaries set by time, modes and means, and a living of life with the time one has. In one way or another, most of us live in charismatic time. We are aware of the risks we take every day: by getting in our cars and driving on the freeway, or letting our kids ride bikes in the neighborhood. All these things can lead to accidents or end of life, yet we do it. Living takes a certain level of trust and being able to function despite our inevitable demise, this goes for all of us, and most of us

don`t go around thinking dying tomorrow is likely. Still, when presented with a prognosis stating that your child will not survive early childhood, it brings an awareness to the *here and now*, and how fragile life is. This challenges our perception of time. The movement from limited time as perceived by the prognosis, to possibility of more time when entering the Syndrome-X Family, is a re-challenging of the concept, and it shifts from an isolated experience on behalf of the family, into the collective knowledge of the Syndrome-X Family. It also re-defines the condition from terminal-, to chronic.

As the taken-for-granted time disintegrates after receiving the news of prognosis for Syndrome-X, it resonates with what Pierre Bourdieu (1977) contends, that "Seeing doxa in such cultures as a field, or as 'epochal' has the corollary that in 'crisis situations' doxa as 'the universe of the undiscussed' (p. 168) may break down radically (Myles, J.F, 2004). The things we take for granted become pushed to the front of our experience, as we start to question life itself. Knowledge then becomes a way of unifying experience into a coherent whole, where the experience of what life can be in terms of time and possibilities changes shape and takes on new directions.

These shifts in perceptions connect to shifts in knowledge. We have seen through this chapter how the understanding of time to live, and possibilities of belonging and sharing experience, have shifted from birth and diagnosis, to finding and joining the Syndrome-X Family group. These shifts have come about as consequences in changing knowledge about the syndrome, based on diagnosis and subsequently forming relationships with others who share the same role as a parent of a child with the condition.

Hope manifests itself through these processes of knowledge, within these drastic shifts in perception of time and possibilities. But that is not to say that the time prior to membership is equal to an absence of hope. As we have seen, actively searching for a diagnose, and after this searching for others who share the same experience, are *acts of hope*. These acts presuppose that there are answers out there, that there are others out there. Waiting and searching is not done without some trust in the fact that there is something-, and someone to wait and search for. As you will recall from Miyazaki (2004) and his case of the Suvavou people, the act of sharing their knowledge of impending compensation, or reaching out for answers to government officials, placed hope in abeyance. In the wait, in the search – hope is in abeyance, in suspense (Abramson, A ,2008, p.531).

Trough the shifts in perceptions, and from isolated experience to membership, the members of the Syndrome-X Family end up belonging to a living knowledge tradition where the relationships are based in "knowledge transactions" (Aspen, 2001), embodied in processes

and activities within its circulation. The next chapter seeks to explore some of these processes and activities, looking at what makes sharing knowledge possible, and knowledge perceived as valid, and how it is shared and compared between the family members, also trough hope and the narrative of a shared journey.

4. A SONG OF KNOWLEDGE AND HOPE

In the last chapter, we were introduced to the participants that will be the main voices throughout this thesis. After following them through processes of knowledge and hope in abeyance, moving in shifts of perceptions of time and possibilities, we now enter the Syndrome-X Family group. In this chapter, we will journey through various aspects of sharing and using the knowledge they now have access to. We will look at different processes and activities that make sharing knowledge possible, and how the knowledge is used and acted upon. We begin with looking at a process which determines validity of knowledge, and that establishes the foundation for sharing knowledge: familiarity.

4.1 When you see it, you know

Under a post in the Family Group introducing a new family member, Miranda made this comment:

> *It is a privilege to have a forum that allows us to watch our Syndrome- X beauties blossom where they are planted*!"

Miranda`s quote alludes to the notion that wherever the children are born in this world, they come from the same *seed,* a shared origin somewhere unknown. Coming into the group and seeing how similar the children are, is often described as finding lost relatives, or seeing them as brothers and sisters. When membership is granted, the parents start to partake in the activities of the group: sharing knowledge, answering questions, sharing photos and videos as glimpses of everyday life. They celebrate each child`s birthday with a post, and the families also receive personal birthday cards from the Syndrome-X Foundation. All the big happenings from starting school, learning to walk, or celebrating a bat mitzva, to having a major surgery or significant changes in health are shared within the group. The photo album in the group is dubbed "The Family Album." The album contains photos of the children as newborn, to snapshots of everyday life: like a walk in the park or playtime with friends. There are also photos of children on their way into surgery and waking up in recovery.

After 19 years, being able to see other families, to see photos and videos of the other children, was a very moving experience for Lisa. She said: *I don`t even know if I have the words to describe how it felt when the other members started joining the group, and I saw all these gorgeous, pretty little faces and [Lisa starts to cry] …people who look like my son…I just, you know my heart was just like…woah, awesome.* It is one thing to know that there are other families like yours out there but seeing them adds a new dimension to the sense of familiarity and belonging.

Whenever someone new added to the group, one of the administrators make a post of introduction, introducing the new family and some of their backstory, before admitting them. The process from being found or finding another family, to being diagnosed, invited, and introduced to the group, can be thought of as a *rite de passage*. The confirmation of diagnosis and proper introductions its rituals. It is customary for the new members to make a longer introductory post once they are admitted into the group, and to interact with other recent posts made by other members.

I asked Lisa about the criteria for membership, as she is one of the administrators. And I asked about whether there were many who tried to join, as the group is relatively unknown and private. She told me that not many had tried to join apart from those who do have the diagnosis, as is a requirement for membership, and that they "check up on" new members:

…you know I think it`s only one person we did not admit, it was one of those things where …uhm (weighs words)…there just seemed to be something else going on , you know besides wanting to be a part of the support group, and her child did not look anything like our children with Syndrome- X, you know, so we just didn`t let…that`s the only time we`ve said no to a family...

Physical likeness in the children becomes its own criteria of assessment of who belongs in the Syndrome-X Family, as a fast track for determining the validity of the claim that the diagnose is set. After Lisa founded the group, members started pouring in. The numbers might not seem large to the ordinary reader, as we often can equate large memberships with thousands of people in social media groups. But here, in the world of the *rare*, reaching a hundred members has been a great milestone.

Ivana from Russia wrote this in the group when she was added:

Hello everybody. We are new in the group. We found out about our child`s diagnosis previous year, then I said: My child found new relatives. Thank you for that group!

These are some of the comments she got:

Brad: *Welcome to the group. This is our son. We are excited to have you as a part of our Syndrome-X Family. We live in the USA. [Attached is a photo of a boy with short, chestnut hair and big, blue eyes, lying in bed connected to a breathing machine, he is smiling and surrounding the bed are stuffed animals and a print of a baseball is seen on the wall behind him]*

Astrid*: Hello from us her in the North, with family. [Attached is a photo of a little girl with blonde hair and bright, blue eyes, sitting in a child chair next to what looks like a kitchen table due to the refrigerator in the background, smiling.]*

Lina*: Hi, I am Lina`s daughter! Welcome to this big, beautiful family. [Photo attached of a girl with brown hair in a ponytail and big, brown eyes, in a car seat, smiling].*

Usually, those who comment on an introduction post attach a photo of their child. It is my interpretation that the attaching of photos to welcoming comments are *acts of visibility*. It is not only claiming familiarity trough membership alone, but showing it trough the physical likeness, yet individual expressions, of each child.

Through our first conversation, Izobel and I have both shared our journey from birth to finding the family. It strikes me how we both speak about such challenging life experiences so matter-of-factly, but at the same time keeping a safe emotional distance by speaking of it like we would speak about an election, or the weather. But when I ask her about what it was like seeing the other families and children, our conversation becomes more emotional.

It was like lightning striking…the last years have been a lot about survival, and… it has just been really great, … it just feels so good to have other moms and families know what we know, just to have others you know…there are bonds, when I first saw the kids you know…there`s something already there…and seeing the other moms and what they go through, it helps me in times when I feel alone…just knowing I can reach out, check in, and I am not the only one going through this…

In just seeing the other kids that looked like her son, there was "*something already there*." Astrid mirrors what Izobel talks about when becoming a member of the group, as this experience of familiarity and understanding:

It is very heftig[5] *you know, and you just feel this great cohesion when you find the group…that all the kids look alike, everybody understands.*

[5] *Heftig* is a Scandic word used to describe something as being experienced as intense and/or overwhelming

Astrid also highlights how the children look like each other. It is not simply just the shift in knowledge and perspective of lifespan, and finding others, which bind people into the Family Group, but also this recognition of *likeness*. Finding someone who you can see yourself in, not just in shared experience but also visually in the children themselves, - a visual proof of the shared condition. This raises some interesting questions in terms of this group and their use of the term family.

Katherine is a representative from the Syndrome-X foundation and has been a part of the Family Group for two years. Her main tasks are to inform the group about upcoming events, ask them to participate in surveys, welcome new parents, and she also makes a newsletter to send to the donors of the foundation. Katherine's involvement has become quite personal for her, and when I asked her about what she observes when spending time in the group, she replied:

When I read in there for the first time, I already felt that family part. It was like they all know each other, and they were open, and it was nice to see. It is touching how they help each other. In spite of the distance, they have geographically, and they feel so connected in the digital group.

What constitutes a family? There are several themes that can be identified from Katherine`s answer: openness, support, *connection*. Katherine mentions "*I felt that family part*," meaning family is also described as a feeling, an affective experience of belonging. When I asked Ivy, who you might recognize as "the blog mom" that Astrid found, what *family* in this group meant to her, she replied: *In this setting, family means to me a group. A group of people who share a unique and personal connection through our children*. It is the connection trough their children which has forged them into a family unit. Astrid also touched upon this in how she viewed the similarities and connections within the group:

Yeah, I can see that several people in the group mention this about following their own timeline so to speak, and also this family connection in the sense that the children look so much alike. I remember this as well when we received our diagnose, and got to see the other kids, I was like;" Oh my, that`s my child!," they are so similar! When you see it you see it, you know.

When you see it, you know. After entering the support group, all express awe of how similar the children look. There are certain facial characteristics that make them look like they could be biologically related, which is interesting when considering the use of family terminology, both in the name of the group itself-, and the use of the terms like relatives and family when

posting updates, celebrating birthdays, or introducing new members. Astrid pointed out how attending the Family Meeting solidified her experience of similarity:

Oh, it was very emotional. My child was so similar to two other girls, from France and Netherlands, and they are both older; but their appearance, the way they behaved and moved, movement pattern was the same. They just sat there and played, and then… my child has curly hair, and many of the others had curls as well, it was like sitting there watching a twin. It was very special, but very emotional.

Signe Howell and Diana Marre (2006) wrote about transnational kinship and adoption, comparing Norwegian and Spanish families who adopted children from Asia. One of their main findings were that physical and non-physical traits could be perceived as biological, even though the children shared no biological-, or ethnical similarities with their adoptive families. The traits could be anything from dimples and curly hair to a certain manner of being – a physical proof of familiarity.

"In European and North American understanding, it is assumed that children take after their parents, or other biological relatives, in a variety of ways. Such an understanding is based on a notion of shared blood and shared flesh." (Howell & Marre, 2006, p.306)

The Syndrome-X children share both physical and non-physical traits: they look like each other, and they are all described as happy children. The one doctor who is specialized in the condition even referred to it at one point as "The Smiley Face Syndrome," due to their smiling and happy demeanor. Resonating with Howell and Marre not only in findings, but where their findings are located, the likeness between the children can make them appear kin – not merely as sharing the same condition but give an impression of biological relation. Multiple parents describe how, when seeing photos of the other children in the family group, it is like seeing their own children. The choice of the term family then, has more dimensions to it than meets the eye.

Most of the members in the Syndrome-X Family are women. Several participants have mentioned that "*it`s so nice to talk to other mama`s*," or that being part of the group is like belonging to "*a team of moms*." Mother`s day is marked each year with a post from one or several members within the group, and most of the women mention their fellow Syndrome-X mothers in posts on their personal Facebook account and Instagram as well. Mother`s Day fall on different dates across the globe, but it is usually the American one which is marked within the group. Father`s Day has never been marked within the group. The men in the group are not inactive, they just don`t participate in its activities that often.

In studies done on support groups by Rafanell and Sawicka (2019) and Seale, C (2006), they point to debates on how the structural implications of sharing within online support groups can lead to hierarchies, for example trough masculinity and femininity regarding how we share. Support groups often imply the sharing of emotional content (Seale,2006) which is closely tied to femininity, or according to Seale: "women's culture" (whatever that is). This can make such online communities more suitable for women. In the Syndrome-X Family group, one member usually acts as a representative for the respective individual families, and this is typically the mothers. As Rachel stated: *it was a relief to find and connect with other Syndrome-X moms*.

In accordance with the findings of Philips&Rees (2017) on the sharing of bio-medical information in groups which are predominantly female, but deals with rare conditions, the same appears in the Syndrome-X Family. Most of the content, outside of celebrating birthdays and other life events, and introducing new members, are bio-medical in nature. The knowledge transactions that occur are based on knowledge about Syndrome-X: its complications, challenges, treatments, and procedures. This is where we can start to understand the difference between the diffuse sharing in culture and the structured transactions that happen in a knowledge tradition (Barth, 2002: Aspen, 2001). Sharing bio-medical knowledge is the essential activity of a member in the Syndrome-X Family, meaning that cultural differences and contradictions: like religious backgrounds, ethnicity, socio-economic backgrounds, gender, sexual orientation and even language, become secondary parts of group identity. The relationships that form on basis of this membership are rooted in the knowledge they can provide for each other, and collectively produce and share outside of the Family Group. Thus, the knowledge is shared in an agreed upon direction, but adhering to the individual experiences of those who make up the social organization, The Syndrome-X Family.

This relatability, or familiarity, is essential for trust; both in sharing experience, and receiving it. Erving Goffman (1959) stated that "Within a social organization, there exist a team of actors who cooperate on conveying to the audience a set definition of the situation" (p.197). Definition of a situation is both an individual-, and a collective act. It plays out in agreed upon norms and a collective understanding. Goffman contended that what is to be expected in such a group, or team of actors to use his terminology, is a sense of *familiarity* (ibid.). Playing, or acting upon this familiarity enables the respective members to give support to each other and convey knowledge in a way that is perceived as valid and relevant. When

trust is established trough familiarity, the family members can engage in the essential activity of the group: sharing and comparing knowledge.

4.2 Sharing and comparing knowledge

Like Lisa, Lara had gone several decades without finding anyone who could relate to her experience with Syndrome-X. It was after she found Lisa, and subsequently got introduced to the foundation and the group, that she found herself amongst multiple families. She was in awe of what she saw, having been on a solitary journey for decades. However, after being "on their own" for so long, Lara and her family had made peace with the isolation of the experience. When I asked her if becoming a member of the family group had changed anything for them, she replied:

No, but it has been an enhancement…we were on our own for so many years. It is refreshing for me to see everybody and read about things and help where I can. When someone has questions, it is nice to be able to contribute and give information…but yeah, we were very late in the game, so I forged my own path. I was so used to be alone in this…no one had answers for anything…and sometimes, having no answers was comforting, you know…this diagnosis is …it's hard to hear about.

When Lara speaks about how she forged her own path, and how she coped with the not knowing and the lack of community, she spoke of hope as happening in a gradual progression of life. Moving forward and staying in gratitude. She said:

I didn`t say anything about it until my daughter was hospitalized at 13 months. Then we started telling people, because it was just devastating to say… you know… we maybe have only two years and, she is going to be just like those kids … I could not have believed in that … I had to have a mindset, it was just basically how I always was, mindset, move forward, be positive and do whatever you can to have your child have the best life possible.

Being positive and creating a life that is the best it can be for their children is a common thread between the parents in the group. Hope then, also becomes part of the process of sharing and comparing knowledge within the Syndrome-X knowledge tradition. An important part of what is shared is the different treatments, procedures, and approaches to giving the children the *best life possible.* These are practical things which can be communicated in practical ways, making any negative emotion or fear one might have not

shine trough in what is written. Medical language is one such language that is focused on the practical approach to solutions.

The communication within the group is often saturated with complex medical language. It is a language that helps them communicate with medical teams and each other in clear terms. Medical terminology is: "… the universal language of medicine that describes the human body, its functions, diseases that impact it, and the procedures to correct them. Many words in medicine have Latin and Greek roots."[6]. As most parents of Syndrome-X children must relate to-, and learn complex medical terminologies early on, this is a language understood by most in the family group across native language barriers, making it also a universal language in the family group. Apart from the medical terminology and communicating medical knowledge, there is also likeness to be identified in having experienced these medical challenges and procedures, often unique to Syndrome-X.

Although the thing they have in common is being the parent to a child with Syndrome-X, becoming members of the Family Group allows for meeting the other families -, and the children as individuals. The children might look alike, but still they are all different families from diverse backgrounds, from different parts of the world, which come together to share their knowledge and their hopes. The challenges they all face are also different in many ways. When discussing how it was to be a part of this group after other members started "pouring in," Lisa said:

> *Some kids have extra conditions that my child does not have, because each child is so unique, unique in their physicality, unique in their cognitive development, gross motor… it is a wide array, so uhm… you know, it is like a sampling of each, and you know… it was just nice to see other people*.

Lisa does not point to the differences between herself and the other families, or the differences in the challenges their children face as something confusing or out of place. "*A sampling of each individual*" is what the Syndrome-X knowledge tradition is built upon.

For the members of the family group, there are two stories that exist simultaneously: the individual story of the families, and the shared, collective story of Syndrome-X as told by the family group. Individual stories often deal with contrasting times of diagnosis, and

[6] Information gathered from https://www.amopportunities.org/ : a resource page for medical trainees and institutions.

different rights and access to care in the respective countries. As the member group is so diverse, there is bound to be variations of what everyday life with Syndrome-X looks like.

As you may recall, one of my methods was writing topic posts in the group, where I asked questions around a chosen topic, and those who wanted to could answer, and it also opened for a discussion around the topic in the comment section. One question I asked was relating to differences in medical systems:

> *Hi family! Hope you`re all doing well!*
>
> *I have a question: I have been looking into differences in access to health care (cost and alternatives), and I was wondering if any of you would like to share your experience with this? Here in Norway, we have universal health care. This means that all care costs - from surgeries and treatments to medical equipment and care in the home/ relief services outside the home are free up until the child turns eighteen.*
>
> *What is it like in your country? Are there specific insurances that cover your children`s needs? Is it a complex and difficult system*?

These were some of the comments:

> Eva: *We adopted our child, so we have state health care. Normally it`s for low income but adopted and foster qualify as well. It covers all expenses 100% but there is a good deal they won`t pay for. We have to use doctors who take our insurance (most do) and the insurance isn`t good outside of the state we live in (unless there is an emergency). Most private insurances in the US charged a co pay for specialists, but with state health insurance we don`t have any co pay.*
>
> Sarah: *Here in our state [US] … we were fortunate to be in a program with limited spots based on the medical needs. We also both had backup coverage through our employers. We never left our employers or our state to be sure we had coverage.*
>
> Phoebe: *In the UK we are really lucky to have the NHS. We are able to receive free health care for our whole lives. This includes most things that you will ever need from a healthcare point of view. We also get things such as paid carers to help us with our son.*

Michelle (reply to Phoebe):
Although I know far too many parents who struggle to get enough hours for help at home and enough hours for respite. Medically, you cannot fault the NHS but socially, sadly, too many families struggle and despair and become isolated.

Phoebe (reply to Michelle):
Yes I agree, and you actually make a good point, it`s a huge struggle for many to actually get what they need. It also seems to be a postcode lottery for many things. We are lucky enough to get enough hours of care a week, however my son has been on the waiting list for a medical procedure he needs for a long time.

Miranda: *It is a lot to navigate. I remember thinking we entered a secret world that I never knew existed before our son was born. Thankfully there are programs to help navigate, and with social media information and advice more accessible. It`s been mostly positive for us, but I certainly see how the quality of healthcare varies immensely in different parts of the country.*

Siarosie: [Ireland] *The one surgery had 80-euro fee, which I think is reasonable. Our government has only now removed a fee of 80 euros per overnight stay in hospital for children. They want all child health care to be completely fre*
Miranda (reply to Siarosie): *In the US that surgery would cost thousands*!!

Elin: *Here in Sweden, I think it`s the same as in Norway. All healthcare is free for kids under eighteen and after that it`s still very cheap. You don`t pay for surgery etc, you only pay for the days you stay at the hospital. All help with physiotherapy and things as wheelchairs and other aids are free. We also have "caregivers" that in Sweden are called personal assistants that you can get at no cost if you are entitled to it. My child has this 24/7 which is an absolute necessity.*
Miranda: *Many families relocate to our state to be able to use these services. Our system here in the US is absolutely not perfect. The privatization of health care means prices are outrageous and one accident can bankrupt a family. Of course, because our child*

has permanent disability he qualifies for Medicaid, but that is not the case for non-disabled people. I remember when he had been in the NICU for 30 days we received his "tab", and it was 1.2 million dollars… also last summer he was hospitalized his bill was more than 2 million with absurd charges like 116 dollars for a 10 mL saline flush! We didn`t have to pay those bills, thankfully, but it makes me sick to see those numbers.

The numbers Miranda wrote out are overwhelming. According to Adnan Kisa (2021), comparing Nordic and US health systems, Nordic countries has higher life expectancy, lower child mortality rates and better healthcare overall than the U.S for lower costs. (p. 366). The Nordic system, which includes countries like Sweden, Denmark, Norway, and Iceland, sees all persons covered by compulsory social security and health insurance scheme, regardless of social and economic background and situation. It operates on a principle of "free, equally accessible health service for all" (ibid.). On the contrary, the U.S system is a combination of public health and private insurance.

Mina, a US member, wrote that: "In the U.S, every individual is responsible for their own healthcare (minors are under parent's healthcare up until age 25). There are many different options for healthcare, though. Most people get their healthcare through their employment because that is the cheapest route." What becomes evident is that if we are to compare the individual experiences of Nordic and American families in the Syndrome-X Family group, the American families have heavier responsibilities in terms of gaining the right medical aid and covering costs – leading to a higher degree of dependency on employer and state of residence. In the Nordic countries, covering medical costs is a minor- to hardly an issue overall. A family can move from one municipality to another without it affecting the cost-, and access to health care -, financially speaking. The U.S system is based more on individual responsibility, while the Nordic sees the state carrying, to a great extent, financial -, and care responsibility. This tells us, that the Nordic families may have more freedom when it comes to planning their lives, where to live, how much they need to work/ where they work, and so on.

However, when coming together in the group to share knowledge, such differences are seldom made relevant.

The focus is more directed towards types of treatment, what have the other families tried in terms of procedures and ways of helping along cognitive and physical development, and what are the medical practices in each individual family. For example, when considering

going forward with a medical procedure, it is customary practice to turn to the Family Group for advice. Ivy asked this question in the group before going ahead with a risky procedure:

Hello, Syndrome-X Family, asking about this procedure as we need to consider it because of latest development in our child`s health … as you know, it is difficult to decide when to do these dangerous surgeries if we can`t know for sure the procedure will increase quality of life. These were some of the comments:

Satine: *Ma enfant a submit cette operation. Nous avons mis du temps a nous remettre du changement physique qui s`est fait trop rapidement. Mais aujourd`hui tout va bien (smiley emoji). [My child had this operation.. It took a long time to recover from the physical change that happened so quickly. But, today everything is fine.]*

Ivy (reply to Satine): *the doctor did talk about how different my child will look after as well so I`m happy to hear you talk about it. I`m happy it went well in the end*.

Miranda: *Of course, my child hasn`t had it as of yet, but my child`s medical team has let us know that this procedure was very likely in the future for the same reasons (sad face emoji). Hugs as you make this tough decision.*

Standing on the shoulders of such experience-based knowledge offers the parents a stronger foundation when making choices, and it is tied to agency in the sense that it is informed choice rather than being "told what to do" by medical professionals. The knowledge that in question here is not simply about exchanging information in written form, but the *affective* knowledge, which each member has acquired through experiencing living life with a child who has Syndrome-X. I refer to not only knowledge of the health-related issues, what to expect, procedures and risks, but also the knowing of what it *feels* like to have to make these big medical decisions, and live life, with so much uncertainty and little medical scientific proof to rely on. When a member addresses the group with these issues, she does not need to go into detailed explanations about how it feels, or why it is a difficult decision to make; she can say *as you know*, because the community she addresses is a *knowing* community. Sharing within the group then, is safe and needs no elaboration or defense. It means that despite heavy medical information, and often difficult topics in relation to their children, this knowledge belongs within the lifeworld of Syndrome-X. To the family members, sharing and comparing information about a dangerous medical procedure or challenges in development, is normal and expected.

In his study of a family with disabilities in America spanning over decade, Steven J. Taylor (2000), showed how a family where almost all members had some sort of disability, created their own `lifeworld` where disability was not stigmatizing or problematic for their identities. Within their own sphere, disability was the normal, hence a thing of connection in the family. How they have *constructed* knowledge of disability within their own `lifeworld` has bound them tighter and at the same time stood as an opposition to the "outside world." The group becomes a family space, where sharing how one changes medical equipment, or discuss challenges with understanding symptoms, does not need further explanation. Following the family discussions, it is not only about what is discussed, but how it is done. Sharing information and seeking advice on having life-threatening procedures done on a child, requires tact and care. This is true both for the asker, and the one who answers. It also comes down to hope.

4.3 The work of hope

When Lisa talked about the time her son spent in the newborn intensive care unit, she recalled that her father-in-law had come by and said something that had stayed with her*: My husband's dad, my father-in-law, came to see my son when he was still intubated in the hospital, and he hadn`t come home yet, and he looked at me and he said, "You know that kid wants to live!*

The family members often credit the disproval of the prognosis to the innate will of the children, their fighting spirit. Still, when their bodies are working against them, placing hope in an agent beyond their bodies is a strategy often employed. Within the group, prayers are often requested and given, particularly by American family members. Blessings and sending prayers are common comments underneath posts updating about impending surgeries and decrease in health. Eva, another family member from the USA, decided she wanted to make a post specifically for prayers in the family group. She wrote: *So, I hope this is okay, but I thought I would start a post where people could reply if they had any prayer needs. So how can I pray for you*? Eva did not get a lot of response on the post, so she decided to open an external prayer group that members of the Syndrome-X Family could join. After a while, she changed this external group to be an update page for all who want to follow her daughter's

development and their Syndrome-X journey. Several Syndrome-X family members are following the page.

All the procedures and medical challenges the children must face, are at times are a lot to take for the parents. These are often situations beyond their control: handing a child over to surgeons before a surgery, or their children contracting airway viruses, which can be extremely dangerous for Syndrome-X children. To seek out meaning and sources of strength from something greater than oneself is at times necessary.

Lara once gave an interview to a local newspaper in connection with publishing a book. One of the things she spoke of was turning to Jesus, even though her family is Jewish. Lara told the journalist that when her daughter was born, they truly needed a miracle, and miracles was the work of Jesus. Lara decided to give praying to Christ a go. Her daughter has gone on to become the oldest living person in the world with Syndrome-X,

Rita, also an American member of the Family Group, has also been through many close calls with her son, as he has had multiple medical complications on top of Syndrome-X which is not uncommon. When Rita had her son, complications began immediately after birth, and their little family spent the first months in the NICU in uncertainty. The doctors could not find what was the cause of all the problems their child was having. Their family began conducting their own research online, and they happened across Syndrome-X. Rita then wrote:

That was the night I went down to the hospital chapel, and I prayed to God, crying I asked for God`s will to be done, as long as we get an answer to please allow us to know what is wrong. I ended up presenting the information my family found to the doctors and they were able to diagnose him with Syndrome-X shortly after. We struggled with this realization until we were contacted by a transnational genetics center and given further information, information about the other families. There was a 32-year-old alive with this ultra-rare syndrome, and this gave us so much hope for our child's future.

In the suspension of waiting for answers, good or bad, hope is at times sought in guidance from something greater than ourselves. Again, hope is in abeyance, in the space between what we know and the unknown, what we see and what others can see.

Jane told me about the moment she felt her child was given the gift of life, as hope was starting trough run out for their son. She said: *After being told for months that he probably would not make it out of neonatal care, and little progress, we were at a loss for how to proceed. Every step forward felt like ten steps back. On top of it all, my mother passed away. Strangely, right after she died, it was like a light had been turned on in my sons' eyes,*

and he became better and better after that. I still feel like my mother gave her life somehow to him, so that he could make it. I mean, just look at how far we`ve come. I will always be grateful to her for this.

When speaking about feelings and expectations about what the future might look like for her child after the diagnosis of Syndrome-X was given, Jane pointed to how she always knew that her child inhabited way more capabilities than what they were being led to believe by the prognosis. They were simply not visible yet. She explained:

When my child started kindergarten, I was very vocal about the fact that we are the ones who set limitations for him, we don`t know his full capacity…so he has to be able to try everything, and I refused to presuppose that he would not be able to do this or that, you know. Like, I knew that he understood far more than we could comprehend, and he has proven this to be true every day.

Jane also shows that it is up to those around the child to make sure that they don`t create limitations, boundaries for releasing the inner capacities. Hope was resting on her child's not-yet-visible abilities and her knowledge of their existence.

When discussing development, and capabilities to partake in society trough communication, motor skills and social skills, there is never a focus on what the children cannot do. It comes down to what they can do, but the question is how to translate that from knowledge to actuality. When they discuss communication aids, movement aids, educational tools, and the likes, it is always done with an agreement that these are tools to "pull" the skills needed to partake in society, and to be included in it, into visible capabilities. Hope is situated within a knowledge of innate capacities of the children in the Syndrome- X Family, and it is the work of the parents to unlock them.

Lisa knew that her son had the capability for communication, but they simply needed to find the tools to unlock it. Talking about modern communication tools, not only social media, but alternative communication for people who lack spoken language, she reflected:

I, oh I would have given my right arm for an iPad when he was little, oh my god, that would have really changed our world, because the types of communication bars they had were so cloncky and hard to carry around, so we said he is showing us that he wants to communicate so we`re gonna do sign language. And I knew we made the right choice when one time I kinda was walking into his room, and he was in the room, there was even music on, and he was signing, he was signing what he was thinking, are you following? I mean, like little kids might be chattering, you know, he was chattering just with his signs, I was just like "ooh, I think we found the right thing" (laughs).

Like the Suvavou people trying different approaches to releasing "the hidden flow of compensation" (Miyazaki, 2004) trying different approaches to render visible her child`s innate capabilities for communication, Lisa "pricked the taro leaf" in the right place when she tried sign language, opening new possibilities for a good life for her child. A good life interpreted as the capabilities necessary not only to survive, but to partake in society. Not only to be seen, but the ability to be understood by others. Unlocking these not-yet-visible abilities require a lot of detective work on the parent/caregiver side. Researching several types of sign-language, alternative communications, and finding the right tools and aids, becomes shared knowledge within the Family Group.

This resonates with what Bryant & Knight (2019) defines as the concept of *incorporeal materiality:* "Hope harnesses this hidden, but profoundly felt energy- the incorporeal materiality, the unseen capacities of other people and objects – shaping the course of collective action." (p.142). As we have discussed, sharing knowledge about treatments and approaches for helping development, is such a collective action, in terms of rendering the innate capabilities visible to the outside world, and in turn striving for a good life where the children can partake in society, where they can not only be seen, but understood.

Having Ernst Bloch`s definition of hope in mind then, that "… hope is the pursuit of materializing the otherwise than actual" (1959), I argue here that hope is knowing the actual, trough evidence-based potentials of the past and the present, presented as knowledge in the Syndrome-X Family. And the work of hope is revealing the hidden capacities of the children through testing different approaches. Hope is the work of materializing knowledge.

After Lara told me the story about the long road from diagnosis in the 1970`s, to finding the family in the 2000s, I asked her if there was a particular moment she could remember where she felt hope in all that had been difficult. She replied: *It wasn`t a moment, it was a gradual progression of life, of continuing moving forward, uhm. and just, just living, just making it…things go on, you just stay in gratitude*.

Hope is a process. It is a way of approaching the life you have been given. Lara knows this, as she for so long had to forge ahead against the unknown, without anyone else who could relate to the journey she and her daughter were on. Members of the Syndrome-X Family often speak of the *journey* they are on, destination unknown, but the way is walked together, paved by shared knowledge, and the determination and strength of both parents and child.

Looking back to Lisa and her founding this group, it is relevant to note that this group was founded by an American, in an American context. This may have influenced the language, by language meaning how we speak of things, and the temporal direction of the

Syndrome-X knowledge tradition. Cheryl Mattingly (2010) points to what she calls *Disneyfication* in American societies when looking at the work of hope for medical professionals and caregivers in an American hospital, stating: "…Disneyfied children's movies and television shows especially speak to an American myth of overcoming adversity through perseverance, optimism, and *hard work* and, frequently, to the necessity of faith in a cosmological and supernatural world where wishes can come true." (p.177). This points to placing the agency of hope in something external, something that can be communicated, persuaded, and influenced. "While this aspect of American cultural life has been heavily criticized (and for good reason), these cultural myths can be used in subtly creative ways as they are taken up by clinicians and, especially, children and families." (ibid. p.177). A way of creatively approaching perseverance and optimism in knowledge, is a narrative of a shared journey. A family on a joint quest for solving puzzles and discovering the hidden treasures within the children, their shared knowledge as a treasure map.

4.4 A shared journey

> "…healing as tied to pilgrimage is deeply embedded in their way of understanding the situations they face and the kind of story they struggle to carry out. More than any of the other genres, this one speaks to the potential tragedy that haunts hope, for there is no obvious ending to this journey, and, in any case, moral pilgrims may not be able to endure its travails."
>
> (Mattingly, C ,2010, p.76)

The Syndrome-X family is the place to go to *see*, trough comparison and shared experience, possibilities of what their children can be capable of, and the tools to unlock these capabilities. Paving the road together, they have forged the narrative of The Syndrome-X journey, destination: thriving rather than surviving. It is this common narrative that makes the individual experiences harmonize trough success and failure in treatments, getting to know the options for care, and the diverse ways life with Syndrome-X can be approached.

Sharing knowledge is learning from each other, to continue in the same direction: forward. Narrative logic, according to Mattingly and Garro (1994), is "grounded in the

particulars of human action.", and this logic occurs when we "want to understand concrete events that require relating an inner world of desire and motive to an outer world of observable actions and states of affairs. (p. 771). Narrative serves as a concretization of experience and is commonplace in the context of illness to illustrate and articulate experience over time, both past-present-, and future. Ziebland and Wyke (2012) identified this narrative logic, or storytelling, as one domain which affects health of digital support group members: *learning* to articulate illness. In other words, telling a story that makes sense on both an individual and collective level, which lays the groundwork for sharing knowledge and adheres to its agreed upon direction.

"Hope is […] often subject to an often highly moralized, culturally determined communicative etiquette." (Crapanzano ,2003, p. 16). A unifying narrative of Syndrome-X as a journey onwards, provides a way of creating understanding of the experience, both for the one who narrates and the ones who listens. Narrative thus provides a means for creating shared knowledge, and the way the knowledge produced and shared. Hope is a particularly uniting way of telling a story, as hope is a concept which has affective value in the religious, non-religious, rich, poor, and all who know the word or something like it, as it is a concept of common humanity. As Cheryl Mattingly wrote: "Hope is a narrative thing" (1998).

Shifts in perceptions of time and possibilities based on becoming a part of an family group based on sharing knowledge, led us into a closer look at the processes of knowledge and hope that take place after the individual families have become parts of the extended digital family: in a journey through how this knowledge is experienced, shared and acted upon as work of hope. The knowledge tradition of Syndrome-X, however, expands beyond the Family Group. As previously mentioned, the group is situated in a knowledge system. In the following chapter, we will see what happens to the knowledge as it circulates in the system: how it is shared and used, like a song that changes form depending on where it is sung. From sharing content through different social media accounts, to shifting roles of experience and expertise, seeing how the voices of the parents move throughout the knowledge system can tell us something about the impact the group has on its surroundings, and how the shared knowledge redefines what it means to be a parent, and an expert. It can also tell us something about the frameworks for sharing within the Family Group, and how the process of sharing knowledge has evolved trough trajectories of technological-, and social change.

5. A SONG ON THE MOVE

> "… a knowledge must have its wellsprings in individual experience, yet it becomes to a large extent conventional in social circles. And in turn, the processes are whereby these conventional bodies of knowledge assume their locally characteristic shape." (Barth, F, 2002, p.2)

In the last chapter, we looked through the processes of knowledge and hope, at the ways in which knowledge is shared, understood, and acted upon. How knowledge is shared outside of the family group can also say something about the considerations made within it. As you will recall, I talked about what I defined as the Syndrome-X knowledge system. Within the circulation of knowledge is balance between individual and collective stories, and how knowledge changes depending on where it moves. The interaction between the individual families, the Syndrome-X Family and medical professionals speak to the journey from experience to expertise, as the members of the Syndrome-X Family are often the ones who inform and educate the medical professionals, not the other way around. Lastly, we will lift our gaze to how the process of sharing knowledge has evolved trough trajectories of technological-, and social change

5.1 Polyphonic polymedia

Becoming members of the Syndrome-X Family means getting an overview of the other parents, and links to their personal profiles on Facebook and the other social media platforms where they are active. Many of the family members are highly active users of multiple social media platforms, like Instagram, Snapchat, TikTok, YouTube and Twitter. Several of the members also use some of these accounts specifically for raising awareness about Syndrome-X, and for sharing stories from a life a bit on the "outside of the ordinary." Over these different platforms, fractions of their individual experiences are shared, and by exploring this, we can say something about what parts of the individual experiences are made relevant to the collective narrative of The Syndrome-X Family.

Douglas Ezzy (2000) identified three types of illness narratives: linear restitution, linear chaotic and polyphonic. The word polyphonic is defined as: "producing or involving many sounds or voices", derived from the Greek word *polyphonia*, meaning multiple sounds.[7] The polyphonic illness narrative is defined as a narrative allowing for contradiction and multiple different experiences, which is "… integral to the human condition […] and allows for a focus of a quality of life in the present" (ibid. p.615). This also translates to sharing knowledge, and how that knowledge relates to individual experience.

As previously mentioned, the Family Group is a safe space for sharing knowledge – the members understand each other's experiences which releases the individual members from having to explain in depth the whole story of Syndrome-X before asking questions or sharing updates and information. But they also share fractions of Syndrome-X knowledge on other social media platforms. Facebook and Instagram are usually related to sharing experience on a more intimate level, meaning that what is shared is meant for an audience consisting of friends and family, people they know. You-Tube and TikTok are platforms that usually indicate sharing with a wider audience. These platforms used for spreading awareness, and contains more generalized-, and less personal information.

Ivy is active in sharing on multiple platforms, and she runs a YouTube channel intended for sharing glimpses of everyday life with Syndrome-X and raising awareness about the condition. Ivy has been responsible for the discovery and recruitment of several Syndrome-X Families due to her online activity. Looking through her different platforms, there appears to be clear boundaries between what is shared in her different accounts. On her personal Facebook profile, she updates about their whole family, their daily lives, and emotional content as posts describing how it feels to be in the hospital again after a short stay at home. These updates do not translate directly back to the Family Group. In the group, she shares the more bio-medical aspects of their hospital stay and goes more in depth about the actual medical challenge and/or procedure that they are dealing with now. On her Instagram, she usually shares snapshots from everyday life both from the inside and outside of hospital. The videos she posts on YouTube are linked to her Instagram account, as she posts on Instagram every time a new video is up on her channel. She also copies and pastes the caption of the YouTube video to caption the post on Instagram. What changes between these different platforms? The perceived audience.

[7] Dictionary by www.google.com

Spreading awareness about rare diseases -, and Syndrome-X in this case, is about utilizing the scope and reach of social media platforms to make more people *aware* that they do in fact exist, and it can be a way of raising money for research and care. It is also a strategy for advocating for rights and reaching others who have yet to find the Family Group.

When raising awareness, it is usually done through a brief description of the syndrome, and how people can help spread awareness and donate. It is also a way of "owning the story." Before, disability and disease were a private matter (Nicholl et. al, 2017). But now, with social media, people with rare conditions and their parents and caregivers, can use these platforms to tell their story in their own way, and in this way owning the narrative and establishing the discourse society has about the condition.

The information shared on personal Facebook-, and Instagram accounts are also different from what is shared in the Family Group. Here, information is also more "compressed" and made more "reader friendly," and what is shared is usually in connection with happenings: like birthdays, holidays, first day of kindergarten or school, and so on. But it can also take on more of an emotional character than within the Family Group, as the considerations of who is in the audience shifts in accordance with where information is posted. It becomes considerations not based on what technology in form of different platforms with distinct functions dictate – but considerations based in personal relationships. Madinaou & Miller`s (2013) theory on polymedia argues this, as this also aids us in avoiding painting what we see in colors of technological determinism. The technology is itself is a tool, not an act. Sharing fractions of knowledge in a process of considerations are social acts.

Several family members are also active in other, larger support groups across Facebook. There is an extensive amount of such groups available to the public: they can be related to medical procedures or equipment, or to special needs parenting, either belonging to a particular geographical area, or global in scope. Within these groups, the member base usually hit over thousand – if not thousands. Lisa took a moment to highlight the fact that she has never encountered anything negative or any conflict within the Syndrome-X Family Group, which she found highly uncommon. Outside of the family group, Lisa is a member of multiple Facebook groups for special needs parents. She told me:

> *I`m in other Facebook groups where that wasn`t the case, you know, people were …there`s, we have a group of people who are family members of kids with special needs just for parents from my home state, which is nice, we write back and forth and ooh, some people can be wicked! You know, just say things that are like…what? I haven`t…I don`t think I`ve had a "what?" moment, except maybe one,*

there was one person, but they were just posting like….I don`t know , actually I don`t know that much about Facebook per say but, I think she was like posting something that went to all her friends and so it would end up in the support group page and we just had to remind her that this wasn`t the place for this stuff, where you`re doing all your posting, it was just silly stuff , you know?

From what Lisa mentions, one does not simply post any kind of content within the group. There is a divide between what one can share with friends and family on personal profiles, and what is appropriate to share within the Syndrome-X Family. Although there is no description anywhere on the Family Group page of what is expected of the members in terms of conduct, and what is allowed to post and not, there is an implicit framework for sharing to be uncovered. There are norms – an unofficial blueprint for action. It is within this framework for sharing that a member of the family group can participate in the knowledge tradition of Syndrome-X.

To uncover grounds for expansion and constraints of knowledge, Barth proposes an analytical approach where we can identify *the three faces of knowledge (2002)*. These he defines as: a substantive corpus of assertions, a range of media representations and social organization (ibid.). Barth was clear on this matter; the three faces should not serve as a cause for dividing empirical material into three categories and studying them each on their own. They always appear together and are mutually determinant. To look at the division of sharing: for example, a post shared on a member's personal profile versus how the same information is presented in the Family Group, we can see the interplay of the three faces of knowledge. The three faces in my empirical field can be defined as the existing body of knowledge of Syndrome-X, the distinct types of media used to share, preform, and act on different fractions of that body of knowledge -, also including emojis, photos, videos and ways of presenting knowledge. And lastly, the Syndrome-X Family as a social organization. Applying the three faces to specific situations and practices, it is possible to: "[…] observe the interplay of circumstances that generates the criteria of validity that govern knowledge in any particular tradition." (Barth [2002] p.3).

Seeing how these three faces interact: the knowledge, the multiple social media platforms, and the family members, we uncover what parts of the knowledge by experience of life with Syndrome-X become constrained, and what parts are made relevant. Sharing emotional content meant for emotional support is not widespread practice in the Family Group, which is an activity meant for other accounts and platforms. Observing the act of sharing knowledge,

how it is shared in different media, and considering intended audience then, I argue that shared condition and similarities based on a diagnosis of Syndrome-X in your child is what enables a member to share knowledge and partake in its tradition. But the Syndrome-X Family is based on knowledge that is relevant to the bio-medical side of things, and the work of hope in materializing knowledge of innate capabilities. Hence, emotional support for the individual parent and their personal knowledge, based on the feelings of being a rare-condition parent, is constrained by the frameworks for sharing within the digital family. The Syndrome-X Family is not an emotional support group for parents to air their personal emotions around rare-condition parenting, it is a group of experts on Syndrome-X.

5.2 From experience to expertise

It is not natural for doctors to search on Facebook or Google for medical information, they usually stick to their own data bases of medical literature (Nicholl et.al, 2017). This has in large part to do with the question of what we can call a "credible source," which is understood differently from scientific communities and "everyday" life. In the medical, scientific community, a credible source is a textbook or a research paper, knowledge that has been evaluated and tried by educated professionals. Personal experience becomes numbers in a data set, where the *experts*, the medical professionals, and researchers, give them meaning in their own image of a case. You are familiar with the term *knowledge is power*. In the case of being a member of the Syndrome-X Family, that power of knowledge allows the parents to have an overview of available treatments, and a certain idea of what the future could look like. This also comes into play in interaction with the medical community.

After so many years of waiting for the diagnose, and many unsuccessful encounters with doctors and other health care specialists, Lisa`s trust in the ones that were supposed to "know it all;" had waned:

… I still don`t truly trust doctors, I … you know, you have to take everything they say with a … not that, it`s their opinion! So, you just how to sort of evaluate that and how that works with your kid.

A doctor can have an opinion, but at the end of the day, the parents belong to the hearth of knowledge of Syndrome-X, a space where the parents are *the gatekeepers* of knowledge. Most health care professionals will contend that parents are experts on their own children, but to a certain extent. Not when it comes to things like complex treatments and

surgeries. These belong to the domain of *professional knowledge*, knowledge that requires years of medical school and training. But rare conditions like Syndrome-X are not textbook material. Most doctors will never have heard of it if they have not encountered patients with the condition earlier in their practice. This is a condition one gets to learn and understand through experience, by living with it. In the case of Syndrome-X, parents truly are the experts. This leads to some shifts in roles that are usually set in society, the role of doctor as expert and parent as the one seeking advice.

The differences in treatments, and access to them, are shared as experience-based knowledge in the family group. This is also knowledge that circulates into respective medical teams, and other public services involved in the children`s treatment and care. Jane reflected upon how "upside down" she felt the relationship between them as parents and the medical professionals were:

It`s sort of strange actually. I mean… when you go to the hospital with your child, you expect to kind of "hand over" your child to the doctors, and then they use their knowledge and techniques to figure out solutions, and then they might ask you some things about "normal" things like weight, or food. Then, in the end they are the ones who give you advice, an overview over treatments and plan the next steps you know. With us it`s just the other way around, like… we are the ones who have to inform the doctors, not only of the normal stuff, but …all the treatment options, symptoms and signs, what to plan for in terms of development of their fragile bodies… I have seriously taken my child to the emergency room at the hospital multiple times and had to tell them what to look for – things like `he needs an x-ray of thorax, you need to run these or those types of tests… these symptoms require neurological supervision, an MRI`… such things, you know. I have sat in meetings with to heads of surgery and told them what to do. It`s absurd if you think about it. But we`re the experts, so ...

The participants point out that they indeed feel like doctors sometimes, not just parents. It adds an extra dimension of responsibility upon an already heavy load in terms of daily care, following up appointments to a number of specialists, collaborating with schools and having an adapted home. It points to how important this family is: they are not just fellow parents having a shared experience of something rare and unique, they are also a well-educated team of medical experts in their field: the field of Syndrome-X, and of special needs parenting. Or, as Barth would say, the experts of the Syndrome-X branch of knowledge (2002). A strained relationship with medical professionals from the beginning shows up in multiple personal stories from the Family Group.

As Lara told us about feeling that the diagnose was almost “hidden” from them, and their medical team choosing not to do anything and forcing them to go out of state for help. Jane received papers from the 1970s in the 2000s with dire prognosis that was heavily outdated an inaccurate. Lisa felt like they were not taken seriously, while Rita and her family had to go online and search for answers to figure out what was causing medical issues for their son. Most of them had to do their own “detective work” to find a diagnosis, and the correct updated knowledge about it. Now the Family Group is the place they all turn to for advice on treatments, procedures and questions about complications that may be related to the syndrome. This also goes for the respective medical teams of the individual families. Some medical professionals even ask the parents to bring questions concerning treatments from them to the Syndrome-X Family. Miranda posted this question from their pediatrician in the group

> *If your child has received this particular treatment, at what age did they begin? Did they have negative side effects? Our son`s doctor hasn’t treated a child this young (2) with this and doesn’t have experience using it for prevention of damage. He is a very good doctor and won multiple awards, but just hasn’t had a patient like our child before! He is going to consult with other doctors also, to see what they think, but wanted to ask here as well. I know many people with Syndrome-X receive treatments at a younger age than is typical and we always need to weigh pros and cons.*
>
> These were some of the comments:
>
> Mia: *Only thing our doctor has our child doing is taking vitamins and making sure the levels on her bloodwork are on the higher side. At this point he is not concerned yet.*
>
> Ivy: *My child started at age 6, no prior issues with this. Doctor wanted to start because of surgeries she may have in the future. No negatives*
>
> Nadia: *Meu filho já teve os 2 femos quebrados e o braço também é muito difícil isto agora toma doses diárias de uma vitamina com muito cálcio*

The power of knowledge is also a power of choice. Knowledge gives the parents a higher degree of agency when it comes to choosing treatments, and in general interaction with medical professionals. By sharing their own experience-based knowledge with each other, they give each other a wider array of possibilities, and a stronger foundation for making choices that feel right, and safe, for each individual family.

Nicholl et. al (2017), argued that"…media engagement facilitates the emergence of parents who are better informed and empowered, have greater understanding of the management and care of rare conditions, and are increasingly considered experts in their child's care, specifically in how the particular condition is developing in their child [6]; many parents come prepared to health consultations with information sourced from the Internet [1]." (p.2)

In collaboration with the parents and researchers, the knowledge shared within the Family Group has been compiled into a pamphlet named "Standards of Care," that has been sent to several hospitals and all the families in the group. This is meant as an educational tool the parents can use for *teaching* the medical professionals about Syndrome-X. A tool made from the expert knowledge of the Syndrome-X Family.

Becoming an expert group has been not only a product of experience alone, but the opportunity to share it and to be a part of the Family Group online. This shift in experience to expertise then, is also based on technological developments, a change over time in access to knowledge, and to others who share in that knowledge.

5.3 Trajectories of change

When I asked Lisa about what she thought has been the most significant change between when her son was born and for the Syndrome-X families that receive their diagnosis now, she replied: *We didn`t have a computer, we didn`t have Facebook, we didn`t have… let`s see other things you guys have now (laughs) that we didn`t have. I mean we were spittin` in the dark back then you know, so…it means a lot.*

A trajectory is defined as "a connected series of events, actions or developments." [8]. Social media, as we have discussed, has not always been around. The sharing of one's own knowledge and navigating a digital field is natural for some, and new to others. From *spittin` in the dark* to social media, this has an impact on the individual experiences of the Family members. When Lisa and I were talking social media and membership in the Syndrome-X Family, she said:

> *I think the way it works now, most of the time, is that when people do get the diagnosis they really can`t join until they have a diagnosis now which is kinda sad , but you know, again I….maybe we should throw it out to the group…but in the beginning,*

[8] From dictionary: www.vocabulary.com

Martha, Linda and I , and someone from another state can`t remember the name, we decided that we wanted it [the group] private. And to be invited , we didn`t want people to be able to grab pictures off of the Facebook-page and , you know, splatter it over the internet, and I don`t get that impression from the new families now, because they , they`re posting….I mean have you seen Miranda, I love her, uhm…she posted on her Facebook page about how to [change medical equipment] , it was just like "Wow!" (laughs) so…it`s a whole new world!!! And the family from the northern state, uhm, she (Ivy) keeps finding people, you know, on the different interactions she`s had on other Facebook-pages and invited people to the group.

The shift from rare-condition parenting as a private family matter, to a collective matter of transparency and openness, has been one of the most significant changes and a product of social media. As Lisa said:

When people criticize Facebook, I go: "Yeah, but I have this group" (laughs) there`s no other way to be in touch with them. I don`t hate on Facebook, I think it`s great

Lisa was not always positive to being online, however. She was skeptical to sharing photos and things from their lives on the internet, as it could "*get splattered everywhere*." For her, online space seemed like a space without borders or systems, where everything shared becomes a part of the public sphere. It was her friends who convinced her to try creating a private Facebook group after her difficulties with navigating the website belonging to the Syndrome-X foundation.

Lisa was amazed to find so many people "*there on Facebook*," and it also gave her a glimpse into the lives of the others. She was fascinated about what they were sharing, how open they were about their children`s condition. She talked about how strange it was to see how often the other parents were on social media, some even showing with pictures how they use medical equipment. It was a new world that was opening, where before conditions and illness were something to hide, or at least not talk loudly about, but now seemed to have shifted into something we share and raise awareness about. Both Lisa and Lara had strong opinions about social media and *being* online. Talking about when Lisa decided to start the group on Facebook, Lara said:

It was that idea because we could not always get into the website…. I don`t know why, but Lisa suggested going on Facebook, and then…. Here we were. And I never wanted to go on Facebook as I told you…, she [Lisa] said oh it is a private group, I said I don`t care, maybe my co-workers will find me somehow, I don`t know.

And I was reluctant for years to join. When one of my sons joined, and then finally I did. So that was it. Yeah.

The misgivings both had with social media quickly shifted as they started to get to know the others in the group and as they started to feel safe within this closed online space. For others, seeing Lisa and Lara in the Family Group was a guiding light, seeing their kids who now were adults. They were the living proof that the original prognosis had been wrong. The sharing of photos and information Lara and Lisa had been worried about, proved to be of the utmost importance.

Trough processes of change: in perceptions of time and possibilities, trough sharing and comparing knowledge fragmented over multiple platforms, in the changing roles of parent and expert, and through trajectories of technological and social change, the song of hope and knowledge has traveled forwards in shaping- and being shaped by the Syndrome-X Family. All seems to well out into the goal of a good life, with the right care, and possibilities for partaking in society. But what happens when member of the Syndrome-X Family loses their child? Does the song end?

6. A SONG NEVERENDING

"Death ends a life, not a relationship." – Mitch Albom (1997)[9]

As we have seen, perceptions of time and possibilities – moved through moments of hope, has deep roots in how knowledge changed from the moment the parents received the prognosis or did not have access to others who had lived long, full lives with this syndrome-, to becoming a part of the Syndrome-X Family and embarking on a shared journey. Technology and social media have not only made it possible to join in sharing knowledge across time and space, and to shift our understanding of experience and expertise, but it has also made it possible to change the way we understand presence, absence, and the role as a parent. Technology allows for a continuation of sharing and belonging – even after life.

6.1 A goodbye to brothers and sisters

When we talked about the affective experience of partaking in the Syndrome-X Family, Astrid said: *... you also get very moved when someone in the group passes away, it`s extra hard because you get so reminded that it`s all so vulnerable, you have to take care of the time because you do not really know*.

To lose a child: describing the feelings, emotions and articulating them in a way captures its essence is not something I can even begin to claim that I am capable of. All I can do is to try to understand what happens in terms of group membership-, and the precious, experience-based knowledge that is left behind. A part of the reality of having a child born with an ultra-rare condition which is considered serious, is the knowledge that there is a likelihood of you as a parent surviving your child. Often, this is what we can perceive as what stands in opposition to what the sharing of knowledge and the work of hope tries to do. But, as we will see, end of life is not equal to the end of sharing knowledge. It is not the end of hope.

As hard as it is to know that the Syndrome-X life is fragile, it is a part of everyday life for the families. The passing of a child is one experience which is not shared by all members of the family group, it emerges like a separation in experience between those who still have

[9] From the book Tuesdays With Morrie, by Mitch Albom, 1997

their children, and those whose children have passed away. They exist in the same group, they communicate, and they participate, yet they relate to two different sets of reality: present life as a caregiver and/or family member, and on the other hand, life as the keeper of the knowledge and memory of the child that has passed.

Imagine a classroom, where after the teacher has left, the students never leave, but keep producing and reproducing the body of knowledge the teacher has introduced them to. That is one way of looking at an online community which is always available and where presence is continuous, - for parents where the child is the teacher, even after life. As there are such few known cases of the syndrome, deaths do not occur often. I had to go on a search through the group posts over time, where I found several announcements informing the Syndrome-X Family of children who have passed away. Miriam, who became a Family Member shortly after her child had passed, wrote the following post in the group:

> *Dear Syndrome-X Family, with an extremely broken heart, I want to let you know that my child is no longer with us. She passed away last week. We miss her so much, I had 12 happy years with her.*

There were no photos attached to the post, and it was clean text with no emojis. Miriam only shared this post within the Family Group. The other group members commented with their condolences and compassion, and he who calls himself Grandfather wrote:

We are so sorry to hear of your child`s passing. It is always heartbreaking to hear one of our little Angels is gone. We all share in your sadness and heartbreak. Grandfather.

It resounds in his comment, saying "*one of our little angels*," words showing how this child has belonged to-, and impacted a community of peers. Martha, a family member from the Netherlands and a representative of the Syndrome-X foundation, had not seen the post made by Miriam, but she had found a news article relating to the child`s passing and posted this in the group, with a link attached to the news article:

> *A lovely girl with Syndrome-X has passed away. We did never meet her, yet again we know who she is, because children with this syndrome are all brothers and sisters, not only outwardly but also inwardly. Resilient children despite their limitations, always present, sweet and happy.*

In response to this post, Carol, another member who`s child has passed away, replied:

> *I read this, and it made me smile. It was like reliving our life with our son. He was always home with us and laughing right up until his short life ended peacefully. My heart goes out to the family who now has a child with them in spirit.*

When Carol mentions "*like re-living*," it resonates back to how the children's lives have so many similarities, which make the members recognize their own children in the other children, and themselves in the other parents. A day after Martha shared this post, Miriam responded to it, writing: *Thank you, Martha, for your kind words. I cannot even express how much I miss my child. It is sooo hard without her. She was such an inspiration and joy to be with*. And then, in another separate post, Miriam turned to the whole group: *To my Syndrome-X Family. Thank you for your messages. I don`t have many words at the moment. I wanted to share some pictures of my daughter*. She shared five photos of a smiling and laughing girl seated between her parents, and each photo had multiple heart reactions from the other group members. There was nothing sad or painful about these photographs, they were moments of happiness and life captured, moments that through these photographs now exist permanently within the Family Group.

Some parents join the group after their children have passed. This is either due to late diagnosis, or that another member of the group found an obituary, or a news article, where the diagnose was mentioned and contacted the family. One of these family members is Carol, and she introduced herself to the group with this post:

> *Hi, my name* is *Carol … some of you know my name. Our son was diagnosed with Syndrome-X in the 90s. We lost him at the age of 13. I love to talk about him and share his life and our lives with others- no one really understands the unique joys and challenges of being "special parents" except other "special" parents. Our children are blessings and like all kids – they will try our patience, have you always looking for answers that don`t exist, maneuvering our respective health care and educational systems – but most importantly bringing us the greatest bonds and pure joy that we will ever know!*

When entering the Syndrome-X Family, it was not because of a need for support and bio-medical knowledge, but her *need for sharing the knowledge* their child had given them. Their knowledge needs a place to belong.

Amber, who`s child was diagnosed shortly before he passed, posted this after becoming a member of the group: *It seems as if everyone on this page has children with Syndrome-X who are still alive. Has anyone here experienced the loss of a child with Syndrome-X?* There were few responses, most of them from other members whose children are physically present. They offered their condolences, but they also mentioned their own struggles, as to show that although their children are still alive, they can somehow still relate to her experience. For example, Micha, a father from Italy, gave this reply to Amber's post:

There have been many scares and hard times and there still is, my son is still fighting, I am so sorry for your loss! In showing that there`s a struggle for those whose children are still physically present in life, it comes across as a form of solidarity with the one who`s child has passed, and here starts the emergence of a new type of discussion within the group, where it is okay to emphasize the hardships and the negatives as a way of communicating familiarity.

Another group member, Ally, points to how the life lived has been a gift and a blessing, saying:

> *We never expected to have our child with us as long as she has been. We have had many terrifying moments and appreciate that she is a true gift to us. My heart aches for you and your family. Your child was blessed to have you for his mom. I`m so sorry for your loss. Thank you for sharing him with us, he was beautiful*.

In speaking about how the children are shared, Ally touches upon something important. In having such a rare condition, each child with Syndrome-X provides essential knowledge for the extended Syndrome-X Family through a process of life, and it is this information based on experience that transforms into the sharing of the child's life. The life this child has lived, and the life experience the parents have because of it, becomes pieces of the larger pathway for the other group members to follow. It is also a road back to the work of hope as materializing knowledge, but this time as visual proof that there can still be life and hope after the loss of a child. Your knowledge is still relevant, it is needed.

In an interview with Katherine from the Syndrome-X foundation, we touched upon the subject of belonging and community. Katherine mentioned a situation while making a list of all the children`s birthdays which had made her reflect on the family group and belonging after a child has passed:

> *[…] then I was making the list in February, and…now I am a bit touched again…I came to a date of a child that passed away last year. I thought, I must do something with this, and then I thought yeah, I`m here for the communication, right? So I looked up the e-mail address of the family, and I just sent an e-mail saying I was working on the dates, then I realized their child passed away, and I was just thinking how do I type this right, because it is very sensitive of course. And she [the mother] sent me back such a nice e-mail, that thank you… and I thought wow, one e-mail, only one message that their child is not forgotten…what a nice reaction! […] it`s every day, daily…it is every day for you, and of course you love your child and it is that parent/child connection and…of course. But it is always caring, and ehm…that is what I realized then and I thought, wow…it is so*

difficult for you sometimes, and you only have each other in this Facebook group and that is the bonding.

The bonding Katherine mentions here resonates with what Carol mentioned about how the children's lives bring "*the bonding and pure joy*." It is an understanding that the shared experience of Syndrome-X parenting is the source of the bond, but it also turns into *bonds of knowledg*e, which keeps adding to the value of the lives lived, and importance of the fact that they were here on this earth.

When I asked her specifically about the members who have lost their children, Katherine replied: *[The parents] They are not leaving the group, when their child passes away. So that means there is a lot of support, still a lot of support and yeah…indeed the children are remembered.*

Under the heading "files" in the Family Group, I find the list of birthdays Katherine had worked on. There are no symbols or other indicative markers showing which children have passed away. They are there, on the birthday list among their fellow Syndrome-X brothers and sisters. In a way, they`re kept alive by being a part of that group of children, and adults. They are embedded in a tradition of knowledge particular to them, and about them, which their lives, however short they might have been, have helped build and grow. In this way, their legacy contributes to hope and answers for those who live on and those who are yet to be born.

Morgan Meyer (2012) writes about *the material culture of absence*, and he argues that: "Absence, in this view, is something preformed, textured and materialized, trough relations, processes, and via objects." (p.104). In this sense, I argue that within the Syndrome-X Family tradition, absence is not equal to empty spaces, or something simply being gone, but absence is made into presence through processes of knowledge transactions.

Meyer points to how, in this way, absence can be traced by; "…following and describing the processes trough which absence becomes matter, and absence comes to matter." (ibid.). The life experiences of one child with Syndrome-X can save another child's life through the sharing of knowledge produced through the child's life that is kept by the parents. The role of the family member, then, continues, yet it changes shape in the absence of the child. What is still present, is the knowledge and hope, a legacy and a memory of the life lived. I define this as *the material culture of the absent*, as here, the changing form from physically present to absent in a bodily sense of the child, does not remove the presence of experiential value the life of the child has taken on in the knowledge tradition. The song lives on.

In another announcement I found, Martha shared the following message on behalf of Michelle:

> *Sadly, Michelle`s son passed away last week. This is the message she asked me to share with you: He had recently had a medical complication, which in itself is something people live with. However, he also had other complications which he eventually could not fight. I have looked in all the Syndrome-X literature and have found nothing documented to suggest it specific to Syndrome-X. Whilst it is so sad for my son and us, please do not worry about your child. My son died peacefully in a children's hospice and the whole family managed to be together. Depending on how I feel, I still hope to join the family meeting next year. Regards for now, Michelle.*

Michelle has a yearly online tradition where she shares a post compiled of photos and videos of her son in the support group. With it are words of remembrance of a young life lived to its fullest, of a love for music and for his siblings. It is a celebration of the fact that he lived. When I asked her about how often she is active in the support group now, she replied:

> *Obviously, in my case I do not use the group to support my child anymore. However, through the years, I believe I amassed a lot of helpful information and knowledge during my child`s growing up to age 18. As well as the various trial and error treatments we had. So now I try to pass on this information and to support others wherever possible. It would be a waste not to pass on whatever knowledge, no matter how insignificant. […] This not only helps me pass on what worked or didn't work for us but also keeps me in constant touch with my son`s syndrome, fellow parents and to be really honest, makes me feel like I am still parenting him.*

Even though her son is no longer physically present on this earth, she is still acting in her role as a parent, now as keeper of the knowledge created through his life. She is still a highly active and distinguished member of the group. The Syndrome- X Family is, like other family units, a space of belonging for Syndrome-X parents, regardless of where their children are. But does this shift in experience by way of losing a child impact how knowledge is shared?

6.3 Balancing knowledge

Even in bringing forth the message of her own child`s passing, Michelle took the opportunity not to bring out fear in the other parents, which shows a high degree of care and concern for the other families. Now, it has been almost ten years since her son passed, and Michelle is still an active member within the support group, sharing her knowledge where she can, commenting on photos and posts, welcoming new members and, sometimes just observing. She is a wise woman, who shows care and concern for each member and their children through messages of encouragement. When I contacted Michelle for an interview, she wondered if she was "*the right one"* to ask, as her son had passed away. I assured her that her knowledge and experience was of high relevancy, and that I was incredibly grateful and humbled by her being willing to share her experiences with me.

Having observed how Michelle responds to different types of posts within the group, as she is a very active member, it points to a fine balancing of when to share, or when to simply support. As she said under our interview: *Sometimes when a parent asks a question on the group, I message them privately so as not to alarm other parents. My son was born in a time when, so little was known. A lot more is known now*. In such cases, she either private messages, or she comments words of support, without sharing information. For example, Donna, a member from the UK, posted about her child having had episodes of "*staring into space and being unresponsive*" and asking whether any of the other members were familiar with this type of medical issue in relation to Syndrome-X. Fearing that it could be seizures of some kind, Donna reaches out for answers. Michelle replied: *How worrying for both of you, I hope you get some helpful answers here.*

When Michelle deems her knowledge as being not relevant or, that it might cause concern, she still chooses to participate, but trough words of encouragement. Carol does the same. On one post from earlier this year, where Evelyn, a member from Northern-Europe, had posted about her child having to undergo a major procedure, wondering whether the other parents can chime with their experiences, Carol replied: *longest day of my life when my son had the surgery. […] They didn`t know a lot back then about Syndrome-X, so did not want to push for more surgeries after that. Recovery was well but about a year after he was back to*

his old self. The surgery improved and extended his quality of life for sure. I wish you the best.

Although Carol admits that the surgery was indeed quite difficult and scary, her focus was on the good outcome and what the positive consequences of that procedure was. Also, like Michelle mentioned in her interview, Carol also points to how knowledge in the medical field have changed, and that processes of change in knowledge over time might influence the level of risk associated with the surgery.

Lisa also mentions "*not wanting to scare*" the others, always balancing what to share and when. Although her son is alive, he was born in a time before the momentous changes started to occur through technological development, and advancement in medical knowledge and treatment. She said:

> *... and I`ve been afraid to post that on the Facebook page, because I don`t want people to worry about things that might never happen, you know, to their kids. I try to jump in if someone asks a question… if I`ve been involved in something similar, I`ll jump in and you know, kinda offer my advice, but the things going on with him [her son] that I don`t understand I don`t…I don`t want to put them on Facebook because […] when the kids are so little, the learning curve is steep and emotional, I don`t want people worrying about stuff with their kids when they are 30, you know, because it might not happen to them… every kid is different.*

Lara also echoes what Lisa states, as she pointed out that "*so much more is known now*", and that the early scares and difficult experiences her child and their family went through back then, belong to a time before the processes of change transformed perceptions of time and possibilities in a life with Syndrome-X.

As discussed earlier, the direction of the Syndrome-X knowledge is forward, trough hope and its work of materializing knowledge. Going "back in time" would in a way be to move in a direction of hopelessness, back to where things were bleak and unsafe. Sharing older knowledge then, would not be relevant to the collective direction unless it is of a hopeful character. It must harmonize with the agreed-upon direction of the process of Syndrome-X knowledge. Balancing individual experiences then, becomes a way of adhering to the temporal orientation of the knowledge tradition.

Leite et.al (2021) argued that: "… hope is considered by parents of children and adolescents with chronic disease as the first and last strategy for dealing with moments of crisis." (p.10). As we have come to see hope in connection with rare-condition parenting and knowledge, both as a direction-, and a way of materializing knowledge, I argue that in this

case that hope is the first and the last strategy of working towards a good life for their children, a way to share knowledge, and a way to live. Knowledge moving in a direction of hope will put constraints on certain types of knowledge. Although an anthropology of knowledge means “the contradictions within one culture” (Aspen, 2001), it does not translate to that all individual experience is *shareable.* The contradictory knowledge based in individual experiences must still *harmonize* with the collective tradition and its direction. If hope is the harmonizing metaphor (Barth, 2002), then withholding knowledge that can thwart hope (Miyazaki, 2004), is to adhere to the knowledge tradition. In this way, the song moves forward, trough life and loss, and trough all its processes of transaction and change.

7. CONCLUSION: OUR SONG

7.1 Summary and conclusion

"We all live lives full of raw and unexpected events, and we can grasp them only if we can interpret them—cast them in terms of our knowledge or, best, anticipate them by means of our knowledge so that we can focus on them and meet them to some degree prepared, and with appropriate measures. Thus, a person's stock of knowledge structures that person's understood world and purposive ways of coping in it." (Barth, F, 2002, p.1)

Through this thesis, we have uncovered the process of knowledge and hope, spanning from the birth of a child with an unknown condition, to being parents of a child who has passed away. Moving with the *salient* processes and activities of knowledge and hope from within the Syndrome-X family throughout the Syndrome-X knowledge system, we have seen how knowledge is produced, reproduced, and used by the both the individual families and the group as a collective.

By way of a distinct temporal trajectory of knowledge: understood as the narrative of a shared journey, and the work of hope as "pulling out" the hidden capacities of the children through testing different approaches-, the work of materializing knowledge, knowledge becomes a song that moves the families together in a community of knowledge and support, moving them in a forward looking direction.

Trajectories of technological change over time and the subsequent processes of knowledge has also shifted our understanding of the categories of *parent* and *expert,* and expert knowledge as shifted from professional knowledge to the parents being the gatekeepers of Syndrome-X knowledge. A shift from experience to expertise.

The processes of knowledge and hope, and the trajectories of technological change, have also re-defined illness as a collective experience, and still being family members as parents whose child has passed away. The material culture of the absent child happens through a process of knowledge, and the role of parent shifts from caregiving to being a

keeper of that knowledge. Thus, inside the Syndrome-X knowledge tradition, knowledge provides a space and place for belonging, and hope for the parents, even after life.

The song of knowledge and hope moves forward, through life and loss, and trough all its processes of transaction and change.

EPILOUGE

More to explore

As mentioned in the introduction, exploring the concepts of family and kinship in relation to the Syndrome-X family would be interesting. Keeping the information that correlate to the findings of Signe Howell & Diana Marre (2006) in mind, the way kinship is understood in relation to rare-condition parenting and digital communities could be built upon by how the Syndrome-X Family experiences the physical likeness of the children, in terms of familiarity. It would also be interesting to explore more in depth the use of polymedia in relation to sharing knowledge about ultra-rare conditions, and how this impacts the understandings of what expert knowledge is, and who has the right to partake in sharing it.

Where does knowledge go?

> "[…] forums (or internet support groups) are a permanent archive of knowledge and experience." (Philips & Rees [2017] p.223)

The body of knowledge within the group, as it grows and expands, becomes a living body. It exists as a product of every member, a body built on experiences of life and death, grief and joy, and strength. What would happen if Facebook suddenly shut down? Where will the body of knowledge go, and can we call it a "permanent archive of knowledge" (ibid.)? An online support group is a fragile body, vulnerable to annihilation by one simple click of a mouse. Over a decade's worth of exchanging knowledge, experience, and forging connections – gone in under a second. We can reflect upon what would happen to that body if the place where it was bound were to disappear. Technology has enabled us to forge connections and to create communities where we could not have done so before, but at the end of the day it still belongs to our memories and is dependent upon that we remember it and continue to build up on it unbound by place. This is relevant not only for this support group, but for all the vast groups and forums that have appeared in social media, especially over the last decade. Where will all this knowledge go?

Historically, pre social media, one could create such a community if there existed a coordinator with an overview of every single documented case of the syndrome, which could make sure everyone had ways of contacting each other. They could be pen pals or be invited once a year to meet in a specific location. But, as discussed in this thesis, many who have found the diagnosis for their child have done so by either researching online through social media for other people with the syndrome, or they have been found through such media. The likelihood of many more children living their lives without ever receiving a diagnosis would be much greater if it were not for the possibility to come together in social media. this is important to keep in mind because place in this sort of situation does matter greatly. Technology is not only a tool or an extension of our social spheres, but also the catalyst and facilitator of forging a community like this in the first place. Twenty years ago, there would be no Syndrome- X family.

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