Take the stage! The management and self-presentation of chronically ill patients with inflammatory Bowel Disease and the bootstrap of social awareness

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Take the stage!

The management and self-presentation of chronically ill patients with Inflammatory Bowel Disease and the bootstrap of social awareness.

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-Dedication-

I hereby dedicate this work to all people whom are diagnosed with a chronic illness, not just IBD. To the people I met. Their stories of coping with illness outside the hospital, but in a new inhospitable social position, have not only touched my soul. I recognise myself in them and they in me. An important steppingstone in our process of healing.

On a professional note:
This thesis could not have been written without the dedication and guidance of my supervisor, Sabine Luning. She has been with me for the long haul. From my first days of sickness in October 2020, to these last days of the academic year in 2023. Whether I was heavily drugged on pain killers, or joining in on the joy of recovery, she always had time to talk to me. And later on, was always there to keep me on track to this horizon. Her kindness, concise feedback, character and laugh will always stay with me.

On a personal note:
To Maaike with love, always.
To my grandmother, for being there, always.
To Hendrien, for the push I needed in life.

Warning: this thesis has largely been written in a restroom, bathroom and/or toilet. Reading it will require an appreciation of modern digital writing software. Let us be grateful that we have passed the time in which writing could only be done on paper.

Abstract

This thesis explores the communication and behaviour of people with Inflammatory Bowel Diseases (IBD) in social situations. Drawing mainly from three narratives spreading from first on-set to long-term living with IBD and a mother whose son has IBD. Furthermore I will also use vignettes from my own IBD-life. Through these narratives this thesis will follow how medical symptoms are unwillingly transposed into social situations, through which people with IBD become aware of how they should present themselves as healthy, while being sick, to prevent stigma and taboos. Also how social expectations of how an illness looks, makes people with IBD aware they do not have any physical traits, yet paradoxical feel the need to perform sick. The focus thereby lies on the behaviour and thoughts of people with IBD. By using Goffman's (1990[1959]) dramaturgical approach as an analytic tool to dismantle social situations and communication, this thesis reveals the loyalty and continuity of the performances to a healthy self-presentation, juxtaposed by the search for a mental or physical back stages where they can be loyal to their illness experiences. I suggest that through these performances of healthy and sick self, people with IBD develop a deep awareness of social expectations that are put on them by others and themselves. Through which people with IBD become entangled in a bootstrap of social awareness.

Keywords: IBD, dramaturgical approach, Patient experiences, Narrative.

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1.0 Introduction

1.1 We all get sick sometimes, but not everyone gets better.

Every month the Dutch national patient organisation *Crohn en Colitis NL* organises several meetings and activities for people living with IBD. Often these events are led by people who have been diagnosed with IBD themselves and have experiences in how to live with IBD. Although many of these volunteers have lost their jobs after years of illness, under the wing of Crohn en Colitis NL they reach out and create opportunities for people with IBD to connect with each other. One of these meetings would proof to be exemplary for the entire fieldwork.

On a cold winter evening (March 2023), I visited a group-conversations organised by two volunteers in a local community centre of Haarlem. I was greeted with a warm cup of tea and biscuits, and sat down at a table in a private room. I was early, but after some small conversation with the volunteers, people started coming in. A few minutes later, nine people were enjoying tea around the table. The clock stroke eight ‘o clock and the meeting started. One of the volunteers started to introduce herself, she was diagnosed with colitis in het 40ties and is using a lot of medication every day. After she lost her job as a teacher she started volunteering for Crohn en Colitis NL, now a year ago. After her everyone followed in a counter clockwise fashion.

There was a middle-aged couple. The husband was experiencing struggles with his employer. He had Colitis, but seemed to be able to manage it as long as he stayed home in the morning. His employer kept planning him in on mornings. Moreover, he experienced little understanding from his co-workers. ‘I know they are talking behind my back. […] making fun of me’ he shared. He introduced his wife, whom he brought for support, while his wife started her introduction with ‘I had to bring him here, he did not really want to come.’ After which she told the group that he was also facing depressive thoughts about his present and future life.

Next to me sat an older man, whose son was diagnosed with Crohn’s a year ago, ‘he is in full denial!’. His son did not want to know anything about his illness nor speak about it. His father wanted to reach out and meet others facing a similar illness like his son and understand how others were dealing with school, friends, even more so, find someone to reach out to his son.

I was next and introduced myself with having Crohn’s disease. I told them that I was *toilet-bound* for 26 months, had been seen by 34 doctors in five academic hospitals. Only the last doctor came up with the right diagnosis. This month was the first time I really come out of my home again. I also told them I struggled with coming back from being really sick and re-engage with studies and thesis. After which I told them I am an anthropologist, studying the social consequences of IBD. I asked them for consent. Which was given with enthusiasm, ‘doctors need to see our other struggles!’ one replied.

Next to me sat an older woman, the other volunteer. She told everyone that for a great deal of her life she has been wearing masks. Masks that would hide her Colitis from others. For twenty years she pretended to be someone else. Until she got every sick with an up flare. After two years of sickness she was deemed unfit for work by the *Uitvoeringsinstituut Werknemersverzekeringen(UWV)* [Institute for Employee Insurance] and told about the struggles to find yourself in '*jobless nothingness'*. But also how letting go of the expectations brought tranquillity into her being.

Next to her sat a couple of teenagers. One of them was diagnosed with colitis, but since she received a colectomy was enjoying all of life. It brought her back to life and was open and okay with being sick, sometimes. She brought a friend for support, a former romantic relation, now her best friend. They both came to spread a positive story to colectomy experiences.

Lastly, an older man diagnosed with Crohn's disease. He received the diagnosis in the early sixties. Back then he received surgery and a large part of his small intestine was removed. He is maintaining remission through exercise and paying attention to his diet. But otherwise did not really feel any consequences.

After the introduction we all gave input about on topics we want to discuss. For some it was 'is there a cure?' or 'How does IBD come to exist?' But others desired to hear how others were dealing with family relations and friendships. Do you tell them? Or what do you tell them? These same questions were applied to work and job application. Personally, I wanted to prepare myself for the examination by the UWV, which will decide my fitness for work and the course of my future.

Though IBD is a medical condition, the questions were not limited to it. They scoped all kinds of personal and social spheres. The relationship between IBD and social struggles lived between us, its examples were dismantled on the round table. One specific example came from the older volunteer.

> *'I could no longer do it…. I remember the tears and panic as I drove on the highway bridge to Almere. I stopped my car mid traffic. Tears started to flow and I could no longer see clearly. In panic I parked the car on the emergency lane. Up to that point no one knew I had Colitis. I made sure no one associated me poop, pain, being sick or stank. I came from work when this happened. Stomach ache the entire day, you know how it feels. So, I was sitting in my car, the seat was filled with blood and excrement, my cloths drenched in it. I lost it. I walked out of my car and screamed for help. The police, the ambulance, my husband came,.. now they know. Everyone that drove by, they now know. I even made the news. I had no choice, all that I kept in, emotions, secrets, they all became public.' – fieldwork note -*

Though she told this story quite calmly, all of us at the table has been there. The point where the pain becomes too much and mental and physical panic takes over. Moreover, the avoidance of being the vulnerable one, keeping it secret. We all followed with similar stories. Probably not only comforting her, but also ourselves through sharing. We are not alone.

The ride home

As I left Haarlem in my winter cold car, I turned up the heater and let the road lights guide me home. Though it is inadvisable to multitask behind the wheel, I started to summarize the topics and people I saw in my head. By now I had been three months into fieldwork, had seen and spoken to 30+ people in real life and online. But this roundtable did not needed a summery, all topics could be found somewhere in other conversations of the past three months. This roundtable of people who will never meet again, exemplified the diverse nature of severity in illness and the variety of struggles that transposed from IBD into social everyday life. Similar to what I had discussed, seen and talked about with other people with IBD. I also started wondering if these people would face similar social struggles if IBD was not present in their lives. Many, questions started to arise. Would co-workers still be talking behind your back? How would your thoughts be influenced by IBD? Would your son be open to talk about health concerns you have him? Would you have to struggle with a '*jobless-nothingness'* and place in society if you did not have a chronic illness? Whatever the answers to these questions could be, something was being constructed that impacted the social lives of people with IBD in a different way.

1.2 From medical patient to people experience with IBD

In the last 150 years medical science has investigated what inflammatory bowel diseases are and how it comes to be in humans. Medical sciences has focused on how to treat an illness. Moreover, provide clear clinical descriptions to differentiate with other *gastro* illnesses.

Medical science differentiates between two subtypes. In 1932 Crohn et al. published their work 'Regional Ileitis: A pathological and Clinical Entity' were they described clinical courses, symptoms and treatments of an inflammation of last part of the small intestine and beginning of the colon. The clinical infection did not fit any known medical diagnoses (Crohn et al., 1932: 583). This became known as *Crohn's disease*. The second subtype is called *Ulcerative Colitis,* discovered by sir Samuel Wilks in 1859 and describes as inflammation of the colon (Mulders et al., 2014: 342). Together they are subtypes of the auto-immune disease IBD. However, the aetiology of IBD is still unknown. Contemporary medical views can be divided in two conjectures; 1. 'a possible genetic predisposition', and 2. 'a possible diet and lifestyle predisposition' (Philipp 2012:2). Epistemological data presented by Kumar and Clark (2009: 285) shows IBD is highly prevalent in northern Europe and

Northern America and much lesser in other parts of the world. The prevalence for CD and UC in North America and Europe is estimated on 27-106 per 100.000 for CD and 80-150 per 100.000 for CU. In the Netherlands doctors estimate 90.000 people to have IBD (Mujagic, 2023, personal communication).

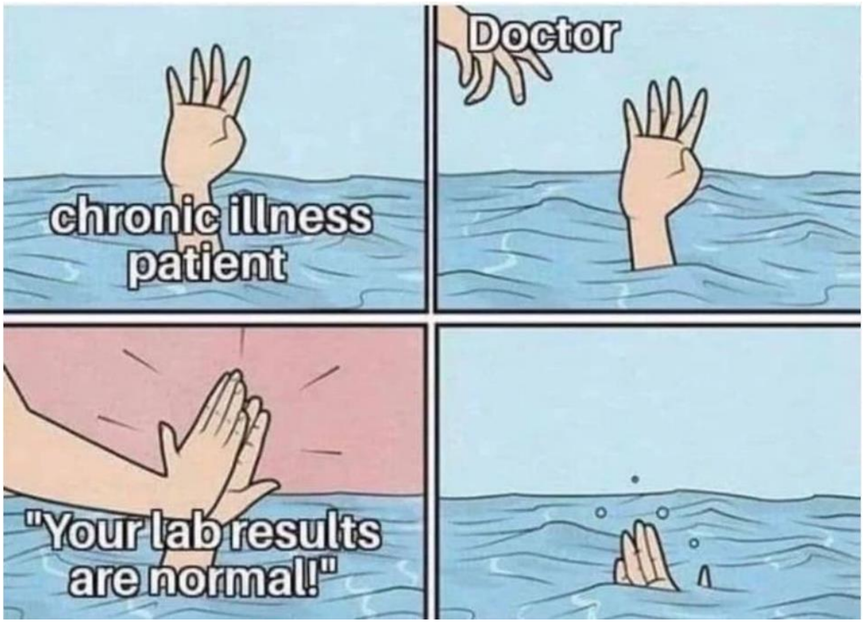
Philipp's (2012:10-28) analyses of nine medical textbooks exemplifies four pathways of treatment: 1. Reducing inflammation, 2. Suppressing immune reactions, 3. Controlling any infection and 4. Supplementing any biochemical deficiencies(ibid:22). These techniques are focused on changing the microbiological pathology of the body. This does not include guidance and treatment of the new social reality people with IBD need to life in. Treatment is limited to the clinical term of a body or *corpus.*

If there are two conjectures of IBD in medical science, genetically or environmentally. One could argue the medical science has been too focussed and limited to the clinical hospital setting, medication, treatment and diagnoses. This constrained focus also reveals an unspoken place for social sciences to investigate the environmental conjecture of IBD. Moreover, scholars in medical anthropology have critiqued the categorical low-value of patient experiences in the *modus operandi* of modern medical sciences (Willen & Seeman, 2012: in Ronsberg, 2019:400). The accuracy of this critique can be seen in the topics discussed in the community centre in Haarlem. Thus demonstrating IBD is not only lived in hospitals, in the medications and the diets people follow. The environmental conjecture in medical view is too limited and can be explored by social sciences. More specifically a social science that sees the contexts of embodiment and interactional nature socio-cultural entities, like Anthropology.

This thesis takes up the call to investigate the underexposed social contextualization of IBD in medical science, by exploring ethnography which portrays how it is to live with IBD and how it influences social interactions. Consequently, this thesis is placed between Medical Anthropology, Cultural Anthropology and Medicine. This also means conceptualizing IBD as a fractional object, with ontological difference across academic displaces. Medical Anthropology has placed itself alongside Medicine to explore the cultural side of illness. Cohn and Lynch (2017: 137-139) have argued the multiplicity of ontologies of a concepts, like IBD, is only limited by academic discipline and the methods. Connections between ontological approaches in Medicine and Anthropology, on IBD ,will reveal new places where IBD resides and create space for interdisciplinary investigation (Christensen, Hillersdal & Holm, 2017: 229). This call of medical anthropology (Cohn and Lynch, 2017) to explore novel ways to connect ontologies is where this thesis places itself. Specifically, this thesis studies the object were these ontologies are lived, living experiences of people with IBD.

This thesis draws lessons from these academic disciplines to define its place and conceptualize IBD by connecting ontologies. It aligns with Medicine to pathologize IBD, which will make clear what physically is going on. From Medical Anthropology it draws lessons of engaging with illness and patient experiences (Cohn & Lynch, 2017: 131), but this thesis does not aim to alleviate the illness or understand the medical and political structures involved. This thesis's goal is to understand how IBD influences social interaction. Most influentially, this thesis draws lessons from Ginsburg and Rapp's (2013a: 52-62; 2013b: 188) experiences of investigating disability 'when it is in the family' and the impact it has on the position of the researcher and the field. Moreover, Ginsburg and Rapp (2013a: 62) argue the importance of introducing disability perspectives on all life domains and see what is common and what is different compared with non-disabled people. Ginsburg and Rapp (ibid.) believe this *disability lens* will enrich and expand anthropological knowledge on concepts and ontologies.

Focussing these lessons in this thesis will provide ethnographic data of chronically ill people with and relate them to anthropological discourses of Identification , Self-representation (Goffman, 1990[1959]), the social function and cultural meaning of Pain (Driessen, 2002) and narrative navigation (Samuels, 2019). Hereby augmenting current anthropological views, but also aiding in the re-valuing of patient experiences in the medical *modus operandi.* The essence of this thesis is to gain an ethnographic comprehension of internal data, thoughts not organs, and personally experienced consequences, not clinical symptoms.



Picture 1: Meme: showing the doctor-patient gap.

2.0 Theoretical Framework: the medical, sociological and Anthropological

As mentioned in the introduction, this thesis takes up the medical and anthropological call to explore the lives over people with IBD and explore a social nature of IBD. This theoretical framework reflects this exploration by hypothesizing how a medical conditions, IBD, is able to influence how people act in social situation. However, this also provides a theoretical challenge, connecting medical discourses on IBD to anthropological views and discourses. To aid in the comprehension of this transposition from medicine to anthropology, I have differentiated three categories. These categories are *Pathological symptoms* (medical description and views), *Expressive symptoms* (what does the patient experience?) and *Social symptoms* (how does it affect social relations and situations).The function of these categories is making clear how IBD travels from the clinical setting, to the personal, to the social one. The first part of this framework will give a thinned description of IBD. By no means is this section a complete overview of medical literature. It is focussed on giving the reader an idea of what IBD is. The second part hypothesizes how the medical patient becomes a person and how IBD expresses in everyday life. The third part, focussed on social symptoms, uses Goffman's dramaturgical approach to theorise how IBD influences social situations, interactions and communication. In this sections the disability lens (Ginsburg & Rapp, 2013b: 62) demonstrate Goffman's approach can be used as an analytical tool to find the social questions.

2.1 Pathological view: a description of IBD.

The literature mentioned in the introduction sketches a brief overview of areas where medical sciences is actively comprehending IBD. Furthermore, it falls short in the portrayal of what IBD is. Moreover, to demonstrate the turn from medical to behavioural in theoretical approach, requires a deeper comprehension of the symptomatology of IBD.

However, this thesis is rooted in anthropology, not medicine. The practical approach to describing IBD below, is a thinned description of a complex illness. Van der Geest (2010: 100-101) describes this as the next step after a thick description. The thinned description does not overlook the detail and context, but relies on it in order to present the bare roots of problem. Moreover, he describes this process of reduction to be linked to the medical process of diagnosis, by not forgetting what is been before. As my personal life is intertwined with IBD, thick lived description is not what has come before, but a simple daily truth.

Symptomatology and pathological processes

As mentioned in the introduction IBD has two subtypes, Crohn's disease and Ulcerative Colitis. The reason they are combined is through their symptomatological similarity. Both illnesses cause acute or ongoing inflammation of the Gastro-Intestinal Tract (GIT) through an auto-immune response. A clear description of the pathological traits and features is given by Crohn et al. (1932). Crohn et al. (ibid:

584) describe the illness to stretch from oesophagus, stomach, along the length of the small intestine, with multiple inflammations and visible lesions reaching into the colon. The ulcers reached through the *mucosa* (the protective barrier of the gut) into *submucosa*(the tissues that absorb nutrients) and much less into the *muscularis* (the muscles that move the GIT). Severe inflammation is able to penetrate the protective layers of the intestine and reach the blood vessels. Crohn et al. (ibid.) also found fistulas to other organs and tissues nearby. A fistula is an unnatural connection between organs through which bacteria and faecal matter can travel and continue the cycle of inflammation elsewhere. Through clinical observations, four pathological features were described through clinical observation, 1.'Acute intra-abdominal Inflammation'; 2. 'Symptoms of Ulcerative enteritis'; 3 'Stenotic Phase'; 4 'Persistent Fistulas' (ibid: 587-588). Why the body activates its inflammatory response remains unclear (ibid 584-586).

Ulcerative Colitis, the other sub-type of IBD, was first described by Sir Samuel Wilks in 1858 (Mulder et al., 2013: 342). Different to *Crohn's disease*, *Ulcerative Colitis* is not only a name, is reveals the place and condition of what is going on. Ulcerative, meaning observable ulcers in different stages of development. And *Colitis,* the inflammation of the large intestine or colon. Though CU is historically the first known type of IBD, its difference to CD makes it a separate diagnosis. This difference being: CD is active in the entire GIT, UC is only found in the colon and rectum. The clinical observation and procedural features described by Crohn et al. (1932) are also applicable to UC. Why UC is only limited to the colon and its aetiology is still unknown.

The similarity in pathological disease course is reflected in the symptomatology of both diseases. Philipp's (2012:10-13) analyses of nine medical textbooks on the symptoms of CD and UC describes eight symptoms of IBD and eight associated syndromes and pathological consequences with IBD. The table below gives a comprehensive account of IBD symptomatology.

Symptoms & Signs	Descriptions
Diarrhoea	Most common and major symptom of IBD. Occurring day and night and often seen incontinence and urgency to defecate, happens between 4 up to 30 times a day.
Stool with (fresh) blood	Major, common symptom in the onset of UC (or colonic CD). The quantity variates from mild to large sums of blood.
Stool with mucus	Major, common symptom in the onset of the disease course. The quantity varies in correlation to the severity of illness.
Excreting blood & mucus alone	Occasional, variation in quantity and composition
Tenesmus	Common symptoms during up-flare period. A constant urgent urge to pass stools. Present even after bowels are empty.

Abdominal discomfort/pain	Common symptom throughout disease course. Wide variety: abdominal distention, cramping, pain relief after defecation, painful rectum and anal sphincter, flatulence, tenderness on palpitations.
Loss of appetite	Common symptom in severe cases, with nausea and vomiting.
Complications	Skin, eye, liver and skeletal complications possibly related to inflammatory process of auto-immune diseases.
Anorexia	Uncommon symptom, but prevalent in severe cases. Also related to weight loss, growth retardation in children and dehydration.
Malaise	Associated with IBD through looking ill, depression and nights sweats.
Lethargy	Associated with IBD through, fatigue, feeling febrile, weakness, lassitude, and exhaustion.
Fever	Common symptoms with variant of low-grade to moderate fever in severe cases.
Tachycardia	Uncommon, prevalent in severe cases.

Table 1: Symptoms and signs of IBD. (Harrison, 1985; Bennett and Plum, 1996; Andreoli et al, 1997; Kutty et al, 1998; Stein et al, 1998; Thomson and Shaffer, 2000; Humes, 2001; Khot and Polmear, 2003; Kumar and Clark, 2009: in Philipp, 2012: 11-13).

Expressive symptoms and living with IBD

This table gives a clear description of symptoms and disease consequences. However, it also exemplifies the expressive symptoms mentioned in the introduction of this paragraph. This functional distinction was made to aid in the transposing of IBD from its biomedical nature to a behavioural and social influencer. This thesis therefore does not ask ‘what are symptoms of IBD?’, but ‘how are IBD symptoms lived?’ How do people live through uncontrollable diarrhoea, tenesmus, continuous abdominal pain, stool with (fresh) blood and/or mucus, while participating in social life and relationship?

Treatment: medical options with social side effects.

There are four pathways through which treatment is engaged to bring IBD into remission; 1. Reducing inflammation through medical steroids or biologicals, 2. Suppressing immune reactions with *amino salicylates.* 3. Controlling any bacterial or viral infection through antibiotics and anti-diarrhoeal drugs. 4. Supplementing any biochemical deficiencies through supplementing vitamins and minerals (Philip, 2012: 22-24). These techniques are focused on changing the biomedical pathology of the body, how the body systemically works, it is not specifically focused on the GIT or IBD inflammation.

Though these biomedical solutions for the symptomatological treatment of IBD are active throughout the human body, they also permeate outside of the human body. During preliminary talks with IBD patients, life-courses and possible futures were changed due to medical treatment for their IBD. Women are advised against pregnancy, as steroids may lead to growth defects in the foetus. Similarly, men were advised against fatherhood as their spermatozoa could be altered due to medicine and result in genetic defects in the child. Also here this thesis does not ask 'What are the consequences of treating your IBD?' but focusses on 'how has IBD and its treatments changed how lives are lived?'

The interplay of symptoms, diagnosis and treatments plays out between doctor and patient. More often inside a hospital. Though the last section hints at life altering consequence of IBD, the medical literature is void from patient experiences of IBD in everyday life. From Samuel Wilks (Mulder et al., 2013) to Crohn et al. (1932) to modern medical texts books (in Philip, 2012) the discourse has been logically focussed on the biomedical entity of IBD, but how this entity is lived is left out of the discourse. Adding a ethnographic comprehension of how IBD is lived to these discourses, would aid in a fuller and deeper comprehension of biomedical social entity of IBD.

2.2 Expressive symptoms and Social symptoms: 'The presentation of self in everyday [IBD] life'.

The dramaturgical disability lens.

Goffman's (1990[1959]) *Presentation of Self in Everyday Life* explores a dramaturgical approach to studying interactions between humans. Throughout his book he uses the practice of a theatre stage to identify the different parts one plays in different settings. However, this thesis envisions this dramaturgical theatre through a disability lens (Ginsburg &Rapp, 2013a: 52-62), which reveals the recurring social negotiations between acting a healthy-self or sick-self. Taking the world as a stage in which social interactions contain expected parts to be played, this thesis connects the dramaturgical approach to academic discourses on taboos and (self)stigmatisation (Defenbaugh, 2012);); how IBD induces mental and emotional states (Sevcik, 2014:84), and envision how IBD is encultured and acculturated in space, time and behaviour (Philipp, 2014: 55-65). By connecting disability discourses to the dramaturgical approach, this thesis creates a dramaturgical disability lens. Which will aid in understanding the relations the fabricated performance and the attributes used to sustain the impression and demonstrate the 'real-ness' of it (Goffman, 1990[1959]: 244).

Furthermore, this thesis acknowledges the limitation of the dramaturgical approach, as it focusses on situational interaction. Goffman (ibid.) made his interactional framework by observing interactions between people. This thesis will also reflect on the entire narrative, consisting out of multiple situations. This thesis therefore implements narrative navigation (Samuels, 2019) as an overarching tool to assess the coherence and negotiations made within the overall narrative of living with IBD and the presentations of self.

In his conclusion, Goffman (1990[1959]: 246) writes about the lowering of the theatre scaffolding though which he was able to explain the dramaturgical approach. This thesis raises this scaffolding again, to explore the people’s experiences of living with IBD through a *dramaturgical disability lens.*

*Performance*s

Raising the dramaturgical disability lens on interactions requires distinctions on how to see the performance of an individual. The dramaturgical approach starts with the question ‘how do I want to be seen or what is expected from me and what can I use?’ All activities during the performer's continuous presence in sight of an audience becomes instrumental to demonstrate and influence the belief of realness and authenticity of their performance. These performances fall into a continuum stretching from ‘the performer believing the forged performance to be real’ into ‘the cynical performance that toys with the audience's perception’ (Goffman, 1990[1959]:30-31). Furthermore, performances are bound to specific spaces and time with specific audiences, ergo a frontstage of work or family life. A front stage is built up out of the *Setting* (physical lay-out, furniture, decor and props), *Appearance* or personal front (clothing, gender, age and shared information) and *Mannerism* (posture, speech patterns, racial characteristics, size and facial expression) (ibid:32,34,39). This thesis will use these dramaturgical concept to scribe how people with IBD are embodying a healthy- or sick-self. Moreover, it may provide descriptions how a front stage or backstage are defined. By imploring these concepts to maintain composure, this thesis also revisions Goffman’s understanding on the stability of a social position. In his argument, Goffman (ibid: 39) point out the stability of Western and European society is depending on the large availability of luxurious settings in which to perform. There are multiple places where you can be a different person. This stability creates proving ground for the persistence of social taboo and stigma throughout time (ibid: 236) as with multiple stage, come multiple expectation of the audiences. As IBD is more often found in the global north (Kumar & Clark, 2009: 285), one can hypothesize that it is this stability is a two sided coin, with a stabile society on one side and high expectations on the other side. From this worldview we can hypothesize that being chronically ill effects your ability to sustain the high societal expectations, followed by a detrimental consequences for a stabile societal position. One can be ostracized from society. Within this hypothesis lies the social mobility for any participant in society. Through a well performed *front* social position is maintained or upward social mobility is gained. This reveals our place in society is not limited to materialistic ownership, a house or car, but also a behavioural conduct of embellishment and articulation of who we pretend to be. Therefore, all efforts and sacrifices must be made to prevent social downfall (Goffman, 1990[1959]: 81,45). It is through this idealisation of upward social mobility that we begin to see, that part of being diagnosed as chronic ill and unavoidable expressive symptoms in social; participation, becomes a gateway of social downfall and loss of social status. Maintaining a front performance is directly influenced by a corporeal illness. The embodiment of a *'cleanliness'* front is therefore essential to maintain any social status (Ibid: 36), but can become unobtainable for people with chronic illnesses.

In Driessen's (2002) dissection of *Culture and Pain*, a similar distinction can be found in *chosen pain* and *pain through illness*. Though IBD would logically fall into the category of illness, paradoxically going through the daily processes of pain and expressive symptoms, while maintaining a clean front, becomes a rite to obtain the presentation of a *healthy self* and painstakingly maintain social status. This process therefore shows large similarities with cultural rites to masculine adulthood, feminine rituals of puberty or muscular pain in athletic sport or performative arts (Driessen, 2002: 47,73,123,135). Also here, we can hypothesize people with IBD implore daily rites to become and perform a *healthy-self*. Which could possibly connect with maintaining of social status. Through this disability lens on pain we begin to see the general cultural expectations of proper western/European behaviour. Defenbaugh (2013: 163) gives some insight into such a picture through the manipulation of her appearance as she describes 'putting on her face'. Here she applies make-up on her own 'death-face' (white, skinny, bags under her eyes) to create a healthy and vital face with an extensive ritualistic make-up routine. Even more so when put into the light of the current online world and the presentation of self on online platforms. In 1959 Goffman based his dramaturgical approach on physical interaction, Paliszkiewics and Mądra-Sawicka (2016: 208) argue the online world to be a stereotypical example of front- and back stages. Thus, raising the questions how people with IBD manage their online identity in a similar fashion or forgery. Or in the case of a dedicated online patient forum, how do they open up or conceal their challenges in everyday IBD life to each other? Are they not on the same side?

Performance teams

Goffman's (1990[1959]: 85) position on teams is defined as the cooperation of individuals in maintaining a single routine as a performance team. This implies that the performance is dependent on each individual of the group. IBD, however, is a non-shareable disease, non-transferable. From this theoretical point of view, people's self-presentation of a sick or healthy self could not become a team effort. The performance is still given by one person, depending on his or her ability to maintain this performance. However, there are supportive characters, people who knows of the IBD and want to aid in any way they can.

Seen only through pathological symptoms, medical staff are part of your team in maintaining remission of IBD. But as mentioned earlier, they do not help in everyday life. They are treating the illness, not the social reality of the patient. Moreover, expressive symptoms are most noticeable by family. But also here, the individual could decide to hide their pain and symptoms. Here this thesis could hypothesize about the continuous burden people with IBD could feel towards people that are close to them. An ethnographic example of this can be found in the Dutch documentary 'F*ck Endo'(Geurds, 2022). Here Geurds (Ibid.) follows people suffering from endometrioses, a medical condition, and shows how it is lived by them. In all cases, the people she followed confessed to downplaying their illness from time to time. To not burden their family life, though experiencing a lot of pain. There is another connotation to be made. The interplay of speaking out of IBD, or make it a topic for discussion and the social taboo through which it becomes a undiscussable. This interplay is strongly exemplified by scholars whom reveal their IBD in their work.

> *'My illness originates and resides in a part of the body that people outside of the medical field are reluctant to discuss lies in parts of my body that outside of medical professions, people are reluctant to discuss.*
>
> (Myers, 2004: 258)
>
> *Consequently, those who live with the illness may be reluctant to disclose it to others for fear of rejection.'*
>
> *(*Defenbaugh 2012: 159)

From these positions, this thesis hypothesizes that in some way IBD is able to contaminate social networks and inscribing taboos and stigma to those who speak of it. In both examples a chronic illness effects the social network and the place a chronically ill person has within it. This thesis therefore explores not if teams are possible, but the interplay between the person with IBD and the people that live with and closely live with them. This *by proxy* view, will reveal if and how IBD travels and becomes a social influencer, not only to the diagnosed.

Regions and Region Behaviour

In the previous sections the front stage has been defined and explored as a region or place for performances in which predetermined standards are upheld and expressed through decorum use and instrumentalization of a self and the audience (Goffman, 1990[1959]: 109-110). However, the previous sections also hint at the importance of a place to draw back to. For people with IBD this place is exemplified by Defenbaugh (2013: 159-160) in her description and use of a bathroom, water closet or restroom. To most people (non-IBD people) this is a function space, used for defecating and peeing. However, for people with IBD it is the place to drop the act, let in the exhaustion and experience the full extent of the embodied symptoms of everyday IBD life. After a while, someone will notice your extensive time on a toilet and one would reconstruct their appearance and continue the performance of not being sick (Ibid: 162). Moreover, the rite describes by Defenbaugh (ibid.) strongly suggests a rite to be lived behind the toilet door. A rite of pain and recompose a self, which is very close to Driessen's (2002) work mentioned earlier.

The dramaturgical disability lens implored by this thesis, helps hypotheses about the materialistic and mental backstage people with IBD search for in everyday life. The example given above, gives a very clear backstage were one is not seen by other. This physical place and time for a *backstage* is very close to the backstage Goffman defines (1990[1959]:114). Within this definition Goffman (ibid: 114, 116) mentions 'no intrusion', 'a contradicted performance in front of others compared to backstage' and 'ceremonial equipment' to be present here. Which aid in to hypothesize what people with IBD implore to maintain decorum, make-up, deodorant, perfume, etcetera. All to maintain a painstakingly fabricated performance of Healthy self. Goffman (ibid.) also constructs an internal backstage, the place where the performance is aware of his or her next move. Or prepares different reaction to implore when situations are not structured or rehearsed. This thesis hypothesizes the physical backstage to always be related to toilet. The mental backstage would be an even more important place for people with IBD. The hypothesis here is centralized around the loss of temporality, people with IBD are always preparing possible situations, and reflecting on past situations.

There is also another side of feeling, the emotional and mental consequences of living with IBD. One can hypothesize feel emotions and difficult mental states as they intrude into social situations where one should not express them. Sevcik's (2014:84) dissertation on the representation and intrusiveness of emotions and mental states in people with IBD, investigated people with IBD, their social circles and related them to the general population. She hoped to gain insight in how to understand IBD as a social entity and not through a medical, or pathological, lens. She conducted several quantitative questionnaires to discern how insiders, people with IBD, and outsiders made sense of IBD and how supportive they can be. She stated the intrusiveness of IBD was not seen as high by people with IBD as they themselves were able to manage IBD. The social circles however scored higher on intrusiveness, not knowing what to do or how to act. Moreover, stigma and labelling, in general terms, is felt stronger in the social circles than by the people with IBD. Moreover, other questionnaire studies also state people with IBD to experience higher levels of anxiety, embarrassment and self-pity than non-IBD-people (Sevcik 2014: 86; Frank 1995: 99 in Philipp, 2012: 14-15). Though her sample size was small (n=146), Sevcik et al. (ibid) discussed the questionnaires to limit the ability to measure the intrusiveness of IBD in social situations and suggested a role for qualitative methods (ibid: 90). This thesis takes up this call, similar in its investigation of IBD as a social entity, but also placing these mental and emotional realities in ethnography.

This intensity of emotional and mental states may also depend on the severity of social consequences of being an object of social taboo. IBD is not a piece of clothing, one that one should not wear. It is physically incorporated into the human being. Other people finding out this dark secret or revealing chronic symptoms to non-IBD-people is possibly opening oneself up to the risk of social stigmatisation, because of the grotesque western taboo of what happens, and what we leave behind, in the restroom (Defenbaugh, 2013: 159).

Thus far, stigmatisation is made clear through examples or the assumption that it exists. This study will explore this process through the narratives of people with IBD focussing on how they are stigmatised. Moreover, if and how they are stigmatising themselves in the process of accepting IBD. Thus, revealing a vital part of *being-okay* backstage.

Discrepant roles

The processes Goffman (1990[1959]: 141-165) described involve several notions of teams battling against one another, or creating subgroups within a group. Both through the pursuit or protection of information. The need for consistency in a (team) performance is juxtaposed by the outing of information that discredits or nullifies the performance. Thus, facts can be overstated while others are understated or ignored. The performer who controls this information controls the group, the more people know this information, the less control there is on outing it (ibid: 141). Goffman discusses three types of secret information. *Dark secrets,* information that is incompatible with the performance. *Strategic secrets,* is ignored and hidden until the performer is ready to reveal it. Lastly, *inside secrets,* knowing this secret makes you an insider of the group (ibid: 141-142).

Seeing these definitions through a disability lens reveals possible ways for *othering, outing* and *stigmatisation* as a communal defence or process. It works both ways. Goffman (1963: 3,49) later describes an invisible physical or mental illness to be an invisible stigma. The revealing of this stigma will only happen under threat or unavoidable disclosure. Moreover, Goffman (ibid.) has pointed out that stigma resided not in any person, but in the relation between performer and audience. This relation between audience and performer with IBD could cause stigmatization as expressive symptoms could cause exposure of an embodied stigma. The motivation to prevent this exposure and prevent a misrepresentation, is found in guilt, shame or fear of stigmatisation (Goffman, 1990[1959]: 65).

As the example in the introduction describes, people with IBD are aware of how co-workers can possibly talk behind your back. This thesis will explore how intertwining IBD can be in professional life. Thus, feeding back into the emotional and mental states backstage, as mentioned in the previous section. The emotional state of *Anxiety* for any social situation more often becomes unbearable (Sevcik: 2004 in Philipp: 2014:15) but how this comes to be, will be expressed in this thesis. Furthermore, the chosen or not chosen outing of the dark secret becomes destructive for social and professional life as taboo and stigmatisation are not exclusive to social circles (Defenbaugh, 2013; 159).

The experiences of people with IBD in professional life have not been thoroughly investigated, as the vulnerability of people with IBD increases not only in their current profession, but also possible future ones. Ethnographic data from this study will scope the stigmatisation of people with IBD on the work floor. A place where teams do exist.

Communication out of character

Goffman's (1990[1959]: 168,173,174,186) view on communications unfitting to the performance of self is based on the communication between team members supporting one-another during and after the performance. He discerns four different strategies. *Treatment of the absent [audience]*, team members will play satire of the audience members addressing them with nicknames. Which is unfavourable to face-to-face. Revealing the difference in addressing the audience off- or on stage. *Staging talk,* refers to communication about the local, type of audience and reception received in collegial solidarity talk. *Team collision,* all collaborative communication shared carefully to cause no threat to performance. Lastly, *re-aligning actions,* referring to purposely hidden signs between members to align the performance during or after a disruption of a performance.

Placing this view on the reality of people with IBD may reveal to be challenging through the often absence of an IBD-team in social situations as mentioned earlier. Though some perspective can be gained from preliminary conversations with people with IBD. In these conversations people with IBD often refer to the IBD as 'a being' on its own, a second entity living in the body and influencing the course of the day. Thus, a corporal language could exist that interacts with the performer. From this vantage point, Goffman's view on communication (ibid.) come into play as people with IBD play a satire of non-IBD-people as '*they only need a restroom once or twice, I am so efficient*'. Or as people with IBD analyse the different kinds of restrooms this world has as a stage talk discussing size, temperature, privacy and more importantly sound proofing. Moreover, when IBD symptoms are labelled as ‘stomach flu*’,* thereby maintaining the general healthy performance and downplaying recurring symptoms as a singular event. Expressing the favourable addressing of team collision. The re-aligning communication between the IBD entity and people with IBD, could demonstrate specific signs (stomach cramps) of when one should improvise a justifiable performance to go backstage.

Though this separation of entities is functional to fit in Goffman’s (ibid.) approach, it also raises questions of the corporal language of IBD in which expressive symptoms may play an important part. This study will create a first outline of this corporeal language in the narratives of people with IBD.

Studying the language involved with sickness or chronic pain is not new to anthropology, medicine and psychology. Medical anthropologist Van der Geest (2004) explores the different ways through which cultures express corporal sensations referring to pain. Throughout the cultures of the world, the language of pain is not defined by its own words. It depends on the words of the surroundings to express what is felt (ibid: 61-63), thereby showing its limitation. Moreover, the inability to accurately speak about the internal perception of pain brings along a paradox, a vicious circle, as this inability often increases the pain. Thereby also exemplifying the mysterious nature and place of pain in the intersection of corpus, society and culture (Driessen, 2002: 43, 166: Van der Geest, 2004:61). Moreover, it gives a legitimate foundation in space and time for the *social pain* that is experienced by people with IBD in this intersection, ergo the inability, the inappropriateness and the deviant culture of people with IBD communicating to each other. The experiences and languages of IBD during a lifetime, may well be an addition to this discourse, as a dialect is a variation of an existing language.

The Arts of impression management

All of the sections above have been instrumental to dissect the challenges and preparations people with IBD are facing in a world of human interaction, in which the upper body often is the focal point for performances (Goffman, 1990[1959]: 244). While simultaneously having IBD in the same part of the body. Thus far these sections aided in hypothesizing on the sum of internal and external processes which could reveal the great artistic skills needed for impression management. Furthermore, it demonstrates this art to be a life-time job without breaks or pauses, as the backstage is not only a place of sanitation[al] relaxation, but also a place of mental solace. Paradoxical, though people with IBD could find themselves torn between the dramaturgical loyalty to unending performances, through social and moral obligation, opposed by a constant dramaturgical circumspection through the awareness of leakages (physical or performative) (Goffman, 1990[1959]:

207,210,212). This mental and corporal inscription may result in a continuous behavioural nature of protective practices in revealing and concealing your IBD to others. While always being aware which form of tact to implore in the expression of the individual IBD narrative (ibid: 222-225).

However in the current possibilities of human interaction, people are no longer limited to meeting in real life. Especially after the COVID-19 pandemic, access to online spaces and online forms of communication and reaching out have been made accessible to all. This also applies to people with IBD. Even more so, people with IBD have the means to communicate with each other online. Represent their self of sick or healthy. Paliswieskcs et al. (2016) have already connected Goffman's dramaturgical approach (1990[1959]) to online spaces, arguing it to be both a front- and backstage. All paragraphs of this theoretical framework can therefore also be put into the spotlight of online behaviour. A transposition where the presentation of self, becomes an avatar. This thesis will explore what these avatars of people with IBD will share on dedicated online space.

From this interactional cornucopia of IBD experiences seen through the framework of Goffman's dramaturgical approach (1990[1959]), a limitation of this approach is found. It analyses interactions on a micro level, *in situ*. Thus a last addition to this *dramaturgical disability lens* is needed, one that sees the narrative as a place of interaction itself. Samuels (2018: 99; Samuels, 2019: 118) uses *subjunctivity* and *narrative navigation* as analytical tools to reveal the need for a flexible past-narrative and future possibilities. This fostering of 'what might be' the past or the future is an important coping tool for people with a sickness or disability as they are dependent on other narratives of their social position and search for meaning. Specifically, the sufficiency of healthcare and social support they receive. Thus, staying loyal to multiple morally conflicting past illnesses, futures possibilities, roles in social worlds and receiving spiritual guidance (ibid: 99; Van 't Hoog, 2017: 36-39). Placing this overarching narrative perspective on the ethnographic data and narratives of people with IBD, would reveal an interesting realisation on how deep the rabbit hole goes and how they navigate the mines of their experiences.

2.3 Conclusion through reflexivity.

I would like to conclude this theoretical framework with a realization. The use of Goffman's dramaturgical approach (1990[1959]) as a theoretical framework has led to a great number of questions and hypothesis on how people with IBD manage their sick and social life. Even more so, it provided an analytical view on connecting academic discourses to possible everyday life experiences of people with IBD. However, Goffman (ibid) was able to spend years in hospitals. I am physically not able to do a similar analysis of social interaction. Answering all these questions and formulating a greater narrative of the complexity of IBD life outside the hospital, deserves a proper investigation. But this thesis will be limited by the daily consequences and challenge my own IBD put on my path.

entity of my own IBD. I therefore have to take into account my physical capabilities both in research question and limitations. I will return on this subject while discussing methods in the field.

2.4 Main research questions and limitations

From the literature review and the questions it has brought to light, this thesis will explore and capture the ethnography of how IBD is lived. This broadness is reflected in its main question:

'How do people with inflammatory bowel disease manage their presentation of 'healthy-self' and 'sick-self' in everyday possibly stigmatised life?'

In this thesis the interactional focus lies upon three domains. First it focusses on the interactions between people with IBD. These interactions are essential to build an ethnography on how people communicate to each other, lose from social sanctions and taboos. Relating these interactions to the framework of Goffman (1990[1959]) will create insights in the process of how IBD is performed among others with IBD and among people that do not.

1. *How do people with IBD interact with one-another face-to-face and how do they disclose (reveal or conceal) their personal IBD expressive symptoms?*

The second focus point is based in the usage of online patient dedicated platforms. This platform is not open to the public, but is monitored by the national society 'Crohn en Colitis NL'. Only people with IBD are able to join this online community. Content analyses of this platform will aid to relate the personal narratives to a larger community. The second sub-question has been formulated as follows:

2. *How do people with IBD perform a healthy-self in social situations, while managing the concealment of their IBD sick self in social and professional situations?*

This sub-question explores the performative nature illustrated in the theoretical framework through the use of Goffman's (1990[1959]) dramaturgical approach. By following three personal IBD narratives of being diagnosed, living with IBD and the impact of IBD on social structures, I will explore how IBD moves beyond a medical condition and becomes an influencer of social situations. By placing these stories in the communal experiences throughout space and time this thesis will differentiate between the common processes and narrative uniqueness. Distinctions that are vital to understand the validity of the personal narratives. Furthermore, it reveals the (self)stigmatisation in their experiences within the medical and social spheres of life. But also elaborates the front and backstage of these interactional situations.

3.0 Methods

In the following chapter I will expand on the methods which have not only led to three narratives on IBD in social situations, but also data that relates these questions to a larger group of people with IBD in the Netherlands. However, first I have to expand on my positionality and entanglement in the field and expose an influential part of myself on my ability to partake in fieldwork and ethnography.

3.1 Positionality – lessons and methodological inspirations

Anthropologists always question their position, the manner of communication and moreover the manner in which they are accepted into places and communities they are investigating. This reflexion helps to build rapport with the site and interlocutors. It is here that I must confess and write about my position in this thesis. Specifically, my medical condition as an IBD patient and reflect on the effects it had in doing research.

For the past two and a half years I have been battling IBD and the aftereffects of a truly hard time in my life. A year ago, I was closer to my grave than living and researching life. Moreover, during fieldwork I was not only planning someone will notice your extensive time on a toilet what ways did my IBD it affect my position as a researcher? And how have I communicated this towards the interlocutors? Moreover, how does this position relate to academic discourses? In regard to the first question, my doctors prescribed me to go back to university and continue my masters. Not because I received a bill of good health, but to stimulate neural pathways that are not connected to the physical perception of IBD-symptoms or continuously trying to make sense of my personal IBD experience through medical journals and dissertations. Engaging in fieldwork and conceptualizing IBD through a dramaturgical disability lens, has been an effective therapeutic treatment to reorganise my being. Though also a painful and difficult one. Secondly, in the past two years I increasingly noticed other patients made a behavioural switch when interacting with doctors, family, friends and or talked about past relations. Here the idea of a behavioural side of IBD found its inception. As I continued to be hospitalized I saw different behavioural possibilities. Just like visiting a new city over and over again, you learn the topography of the hospital and see , as Gupta and Ferguson describe (2012:8), the topography of power. Who has power in the relation, dictates what is expected behaviour. At least I thought at the time.

My position towards my interlocutors and sites has not been singular. I am a researcher investigating the different stages and performances of being sick, but also a fellow-IBD patient. Through this dual-identity I made clear my level of being-native.

Entangled Anthropology

Ginsburg and Rapp (2013) has been a great influencer in this thesis through their work on a disability. They have also been instrumental to the way fieldwork has been conducted. Ginsburg and

Rapp (2013b:187-188) found themselves in a similar position, studying a field of which they are a part. Their children were diagnosed with learning disabilities(LD) and had no educational future, or any support after high school. They saw this as an opportunity to do more than study the research subjects, they became active cultural innovators as they were not the only parents facing this future. They named this entangled ethnography, a reflective approach, which acknowledges their own experiences alongside with those of their research subjects. Ginsburg and Rapp's (ibid:193) introspection and extrospection has led to a deep and clear understanding why topics need to be investigated. It also brought new ethnographic knowledge to anthropological discourses. Shadowing these promises of entanglements are self-advocacy and self-serving biases. Thereby opening doors to misappropriation of the research goals and goals of subjects(Ibid:188). Yet, Ginsburg and Rapp are open about their strategy to support and amplify social innovations, they state ethnography's purpose is to explore and see alternative politics and social institutions(Ibid: 192-193).

This work has sensitized my position in the field. The self-advocacy for a behavioural aspect of IBD was my own inception. The awareness of this pitfall has made aware, that I should not bring this concept into the conversation. But be aware of it through the stories people shared and ask about the effects in their own perspective. Moreover, I have found that a similar disease does not imply a similar understanding of situation. By purposefully asking people how their stories and perceptions were different from mine, I gained confidence not to be serving my own bias on IBD-life. There is however one difference, Ginsburg and Rapp do not have LD themselves. Whereas I do have IBD and will carry into the field.

The insider outsider dilemma

Philipp (2012) encountered a fieldwork where she investigated people with IBD and their perceptions on illness, healing and life, while also being an insider and sufferer first hand. Moreover, her father suffered and died from severe IBD. Philipp(ibid:87) discusses three requirements to deal with the insider-outsider dilemma.

First, one needs to be fully aware of the segregation between the researcher's experience and that of the research subject. Your experience is unique, and this can be said for all IBD patients. The narrative is always unique and should be listened to with naivety, the pain is always personal and does not travel between researcher and subject. Secondly, any knowledge of IBD through experience forms a risk for interpreting the subject's narrative through your own assumptions. This is unavoidable as an IBD patient myself. By being 'sick' myself, I have made a reference framework through which I understand how my IBD works and how it is effecting my participation in social situations. Being aware of this framework motivates me to understand the others framework, and not base my ethnography on my own reference frame. During fieldwork I have continuously questioned my own concepts and experiences by telling explaining how I understand the others IBD. This sensitisation to other perspectives by comparing them in conversation to my own has led to a deep understand in narrative variety. Thirdly, declaring one's own IBD opens up the possibility for sharing the deep and embarrassing nature and views of IBD. Not doing this would be uncomfortable for the participant. The pitfall however is the participant assuming you know what they mean and feel. Or let the participants ask about your experiences instead of the participants' view.

Negotiation of Promises and pitfalls in the field.

Following these lessons from scholars in anthropology has revealed pitfalls and promises of my entanglement to the field and interlocutors. Though after the creation of this awareness, I feel confident about how I have negotiated these pitfalls and promises. Firstly, I have made a reflexive diary, were I shared my thoughts and views on conversations I had. While also reviewing them during fieldwork. After reviewing the second group conversation in January, I realized I fell into self-advocacy for the agency of patients towards the Dutch health institution. This sensitized me to very aware of what I shared, more importantly why I would share a part of my own experiences. In the months that followed I only shared personal experiences when they were instrumental to understand others, or how and why their narratives were different.

On the other side when my insider role was not clear, I experienced conversations to be rough, slow moving and evasive of topics. More so, people I spoke to more often tried to leave things for interpretation, not wanting to explore the topic further. After I made my IBD explicit, the conversations with members of this group immediately changed. Topics were revisited and descriptions of diarrhoea-typology, pain and loss of face, became easily discussed. I therefore argue that people with IBD are more open to talk openly to another person with IBD, then to a person that does not. In reflexion I thought of this as a *shared risk*. When both people have IBD, calling one out on stigma or taboo would also stigmatize themselves. Making the stigma itself worthless. Creating an atmosphere where everything is open for discussion seemed to depend on presence of this shared risk.

3.2 Methods in the field

The previous section about my positionality as a research and insider to IBD, is placed first not only for its confession of my life with IBD. It is also a key part of why I was able to access people in the field, online or follow them three months. Moreover, a promise of having IBD turned out to be sick. Sharing how sick I felt, my visits to the hospital or even being toilet-bound for two weeks, proved to be of great value to people whom I was reaching out (from the toilet). Whether it was me being sick, the interlocutor being sick or we both were sick at the same time. Continuous reaching out from both side, talking about what was being experiences further exemplified how entanglement was not limited to the a similar diagnosis, but also in the places and states conversation continued.

The agenda of the National organisation 'Crohn en Colitis NL'

An important partner in gaining access to people with IBD was the Dutch national organisation for people with CD or UC, *Crohn en Colitis NL*. Through their activity calendar I was able to join online and in-real-life meetings and activities, often organised by people with IBD. During the three months of fieldwork I was able to attend seventeen gatherings and had the opportunity to have casual talks with 50+ with IBD. These talks contained rich source materials in how they dealt with IBD in their social circles and private time. Moreover, these gatherings proved to the place for participant observation, while also participating myself.

During all activities coffee and tea was being served at some point and people started to talk and discuss life and how they were feeling or being dealt with in some manner. More often I took a back position during these moments and observed what was happening and how the conversation were happening. Through these meetings I came to understand why people with IBD can have a deep personal conversation about pee, poop and how to deal with it, while talking to someone they never knew, as if it was a close friend. A prerequisite is the coming out at the beginning of the meeting. Every persons tells their name, their IBD subtype and how severe it is. A confessional rite that will make equals of us all. Moreover, calling out taboos or stigma would also imply yourself, creating trust and safety in a group of strangers. More often I spoke to people who would confess experiencing a restorative or healing effect while attending these meetings. On particular person summarized this as: *'people outside of this group always want to judge us, or try to understand us while putting us in a corner. In this group we can just be, that it, be.'*

During these tea and coffee time moments, not all opinions were directed the same way. After a IBD Yoga class, a group conversation started were two people had opposing opinions of how the social network should deal with them. On one side there was full concealment and secrecy, the other recklessly outing of IBD while going to the toilet 20 times or walk past the que in front of it.

Online platform analyses and chat conversations

The national organisation is also responsible for maintaining a closed online platform dedicated to people with IBD. My first contact with this platform was before the fieldwork, during my 'sick time'. On this platform people share all parts of live that are effected by IBD, not only the medical topics. During the fieldwork I registered every post for one month and clustered them together on topics. This oversight of what is shared online has proved instrumental to relate the narratives of the people I followed for three months to a larger group. This relation gave me a doorway through which I could triangulate the validity of the topics felt and described by them. Not validate the narrative itself.

The second promise of this platform was the messenger board. I could reach out to people on their posts, or *vice versa.* This did not seem to be a fruitful venture to engage with a great number of people, but did allow be to chat with five persons whom shared about their social and family life struggles online. Within these chats, these men and women shared how they would downplay their illness at a given moments, so they could enjoy it without an calling for attention to their IBD. In these chats, my own disclosure as an IBD insider was essential to gain trust and talk about IBD topics. Moreover, with a few of them I had built rapport by telling them what my struggles were with IBD, being a lonely experience and hiding pain. This always led to open chat conversations about other problems. For example, how to raise young children while having IBD, discussing situations where a parent is seated on the toilet with the door open to monitor their child. These chats and insights from online platforms did not bring the depth to understand and exemplify the pathways through which IBD influences the performances of self, sick or healthy.

Following three people with IBD

The greatest and richest source material come from following the lives of three people. Two of them were men, but in different stage of IBD. The first was not diagnosed with IBD when I met him, but I advised him to go see a gastroenterologist. I kept following him as his world perception changed, or maybe even keeps changing. In the course of the fieldwork he continuously reached out to me with questions on how to organise IBD life, while also discussing difficult situations where he felt he needed to hide his IBD from the audience.

The second man had been diagnosed with IBD more than 10 years ago. He knows how to sail with the tide in times of a flare-up. However, in the past 10 years he had to re-enter society several times after a period of sickness. This last year he got sick and lost his job. Eventually he shared his story on the online platform, where he described how his front did not match what he feels inside. I reached out to him and followed him as he started a new job. We had weekly coffee meetings, some for interview purposes, others for hanging out and talk about what IBD was doing that day. I followed his process of going to work. I have used these two narratives to create an overarching narrative that exemplifies how IBD develops into social situations, more over in the reflexivity of people with IBD on past, present and future social interactions.

The third narrative comes from a mother with a son who received the IBD diagnosis on a very young age. She reached out to me on an activity organised by national patient organisation. She heard me talking about the topics of this thesis and was eager to share her son's story. The depth of her story is not only measured by perspective of a mother, but also how her son's IBD made her aware of how she should be seen by her child. We met in the last month of fieldwork. In this month I needed surgery. Which made it impossible to organise an interview. She decided to write down the story, after which we talked about it and I asked questions that remained.

After the construction of the narratives I reached out to all three. Shared their written narratives back to them, which was followed by a surprising threefold feedback. All three felt words were missing or the narrative did not emphasize an experience enough. This led to co-editing the narratives. A process which revealed the strong individuality of each narrative. The meaning of words became very important to them. Though the trajectory of the narratives remained the same. Specific words like pain and descriptions of intimate relationship became very important. Similar to my own hospital experiences the word pain is void. You need to describe where, what kind and its stability. Moreover the paradox between supportive relations and concealing you illness, required a closely edited formulation. A right representation was detailing its importance. A possible notion of staying loyal to both a healthy and sick self.

Modest fieldwork – illness limitations

Thus far I have pointed how having IBD enriches my research position, but also which pitfalls I must be aware of. Apart from these epistemological knowledge, there is having IBD in the field. During the ninety days of field work I recorded twenty-five day when I was hospitalized or sick in bed (or toilet). Another twenty days I was able to do fieldwork, but while being sick. This means that 45 out 90 days I was able to fully participate in fieldwork. Whereas the other half I was managing my IBD and negotiating what I was able to do that day. This is reflected in the limited ethnographic data I was able to gather.

3.3 Ethical considerations and Data management

Thus far is has been made clear that both the interlocutors and the investigator are in a vulnerable position medically (IBD) and socially (fear of stigmatisation). Furthermore, it is not only a feature of a larger IBD population, it is also the interaction of this vulnerability with social situations upon which this thesis bases its hypotheses. This can only be answered by extracting sensitive data from sickness experiences, which when outed feeds back into the already present vulnerability. Being aware of this feedback loop of vulnerability creates an ethical vantage point for ethical conduct while investigating people with IBD. A strong protective factor for the ethical conduct this thesis adheres to, is me being part of the category of people I have investigated and am writing about. Thus, I feel the need to make clear how I have ethically conducted this thesis.

First do no harm, ethics, ethical positions and retrospection.

In academia, especially anthropology, being part of your field in not new, but often part of the awareness process of placing yourself there. Ginsburg and Rapp (2013b: 187-188), who's work influenced this thesis, used a reflexive and auto-ethnographic approach in their entangled ethnography and identified self-advocacy and self-serving-biases as mayor pitfalls in practise. Not consciously attending these pitfalls would be detrimental to explorative research goals and representing the population.

During fieldwork I encountered a 'uniqueness' of every story. A lot of it took place in social situations and opened doors to a social complexity that was different from my own. In practise this led to me telling my interlocutors about how I interpreted their story. Which was always nuanced as my own frame of reference fell short in comprehending their experiences. Furthermore, in writing the narratives, my interlocutors made me aware to the sensitivity of specific words in writing their story. These other frames of references opened up the reflexivity in not playing into self-advocacy or self-serving-biases, by finding the difference between us. Representing the other(ness) remained functionally paramount.

There is however one situation where the potential for harm was,.. tangible. One of my interlocutors, a mother of a child with IBD, wanted to tell me her story. This story was filled with traumatic experiences. At one point she acknowledge reliving the experiences, at night. Which was hard for her and not without tears. The need to share the story was stronger than the avoidance of reliving traumatic experiences. This motivation from her side pinned me to my chair/screen, uttering 'I will listen to what you want to share. You should decide where we go!'

Though supervisors of this thesis have argued that listening to trauma is not unethical. This situation still sensitizes my personal ethics and guidelines. This responsibility over mental state of your interlocutors is a possible consequence of entangling yourself to the field. Even more so, if you share a diagnosis. A notion Ginsburg and Rapp (2013) do not discuss or link to entangled ethnography.

More generally speaking, there a several dilemma's to attend before publication. People with IBD are already in a position of vulnerability through their illness. Moreover, this thesis would state that this vulnerability is enlarged by the social construct of IBD, taboos and (self)-stigmatisation. The publication of personal stories and information could lead to re-identification of the interlocutors and therefore be ethically inhumane. Strategies of anonymization will fall short in protective identity as contemporary search engines would easy correlate the data and aid in re-identifying interlocutors (Thompson et al. 2021:680). Upcoming Ai search engines will further problematize this dilemma on anonymization. Although, the anonymity and protection of the researcher is often overlooked, yet just as important (Zimmer, 2010). Specifically applicable to this thesis as it contains vignettes of my IBD story and my name is on the front page. Making identification a very easy job. These points combined demonstrate the lack of protection in anonymity for my interlocutors and myself.

In my current view of these dilemma's, I see one option: 'a need-to-read' security level. Moreover, I need to see the place this thesis has in the larger context of academia and its pursuit of knowledge. Firstly, it is written to achieve a master degree in science, it will not change the world of people with IBD, nor will it make taboos and stigma disappear. An embargo on the narratives would therefore be logical, in both the function of the thesis and protection myself and the interlocutors.

Methodically, its data would be supplanting and contributing to an academic debate on re-visioning the disability discourses and dramaturgical view of human interaction. More so, it could deepen de entangled ethnography by Ginsburg and Rapp (2013) as this thesis is conducted while also having the same diagnoses. A situation that is very different from 'when it is in the family'. As mentioned earlier this position opens up other consequences in the researchers positionality.

4.0 Through the dramaturgical disability lens

In the following paragraphs I will explore the narratives of Fernando, Daniel and Elisabeth by placing them in the same theoretical framework discussed earlier, a dramaturgical disability lens. However I will start with a person vignette of my own IBD life. I do this, not to implement an auto-ethnographic analysis my own experiences of mannerisms, appearance and setting into this thesis, but to explain the conditions in which I met Fernando and had the opportunity to directly observe the interplay between frontstage, happy and exuberant, and backstage, vomiting and pain. More importantly, it shows the purpose of why having IBD myself made a great impact on my ability to do fieldwork.

> *It was Christmas, the season to be jolly. On December 19th, my partner and her volleyball team organized a Christmas dinner party and partners were encouraged to join. Every couple made one dinner course, which meant roughly seventeen course, from appetisers to evening tea and coffee. I joined in this dinner, knowing I was not able to eat any of the courses, my IBD flare-up made digestion solid food into a painful reality. I dressed up in my best suit, which once was tailored, but now to large. I lost fifteen kilograms and looked fragile. Dressing up I thought this would hide it. Well, up to the point when I would decline all courses and start drinking medical nutrition. Looking goods would diminish the seriousness of my current health.*
>
> *For a long time I was able to play along with the dinner courses. I could hide not eating the first two courses as other were taking the attention of the entire group. One of those moments was the arrival of Fernando, a Belgian guy who travelled all the way from Antwerp to join this night's dinner. He took his place next to me and greeted his girlfriend next to him. As he introduced himself we pulled a prank on him. Speaking in my best Antwerp dialect, I was able to make him believe he was not the only guy from Belgium that night. Well, until everyone around us started to laugh and the ruse, set up by his girlfriend, was revealed.*
>
> *However, playing this ruse, costed me the opportunity to decline the next course. I asked around if anyone wanted something of my plate followed by questions if I did not like fish. I then told everyone around me that I cannot eat solids, that I have Crohn's and made the first bottle of medical nutrition appear from my back. Where I placed my back pack. This called everyone's attention to me and I explained a serious illness, by downplaying the pain I was going through every day. Leaving out the part where I calculated the amount of morphine I needed to go through this dinner. After this spotlight moment, everyone continued the course, all but Fernando.*

> *He was twisting his fork into the fish absent minded. I saw, his girlfriend touched his hand and he returned to the table. Everyone was busy talking and laughing, but Fernando was silent. From this silence among the noise, Fernando started by asking me what my symptoms are, where things hurts, or even if often vomited after trying some food, how I coped with it and I answered then all. The strength of his voice would only reach us two, he seemingly wanted some privacy. 'It seems like you know what questions to ask. Are you experiencing something similar?' He then too silently began a story, but I could not follow it. 'I am sorry if I asked something you don't want to talk about! I really am.' 'No, that's not it. It is just happening this past year, and it's quite odd.' He re-seated himself, looked at his girlfriend and turned towards me, making sure no-one but me could hear his words. 'For the past year I have been experiencing some intense pain in my stomach, just after I have eaten, my stomach cramps up. But it is not always like this. Sometimes, nothing happens at all. My GP tells me it could be stress related, but my life has not been stressful. My life has not changed this past year.' 'Have you ever vomited as a result?' 'Yes.'' 'Have you ever vomited blood?' 'No, luckily not.' 'Well, then I need to say this to you: If you have this recurring pain in your stomach, take it bloody seriously! Go see your GP, follow his advice for two weeks. If it does not work, ask for a referral to a gastroenterologist. Do not take your organs for granted! But Bloody Serious!'*

This outing brought me in a position where Fernando wanted to talk to me, but privately. He revealed some part of an ill-self. But in a manner where only I could and should hear it. This creation of privacy already reveals the small *mannerism* (Goffman, 1990[1959]: 34) he employed in a *setting* crowded with other people. More so, Fernando exemplifies how the a medical ontology of illness through symptoms, is connecting to the social setting by discussing it privately. This brought me to position were only he, his girlfriend and I knew, what a possible consequence could be for him eating these courses. A position that would allow me see Fernando's efforts to avoid something later that evening.

4.1 Performances of sick and healthy self.

In the next paragraph will exemplify how IBD and self-presentation become intertwined. Moreover, I have created a single story line stretching from the first year of diagnosis (Fernando), and living with IBD for ten years, (Daniel). Through this I am able to exemplify the reflexive process people go through after an IBD diagnosis.

The first year, observations before diagnosis.

During fieldwork I was rare able to gather observational data on performances as the changing situations, settings and people proved a personal challenge to maintain focus. Another important distinction is the awareness of someone being sick or having a chronic illness. As this thesis centralizes this otherness, observational data would only make sense if I knew whether someone had an IBD diagnosis or not. There was one situation where I found myself in this position.

After Fernando revealed some of his undiagnosed symptoms to me, the Christmas dinner moved onto 'game night around the kitchen bar'. I retreated to the couch in the living room, viewing the activity from a small distance. In the exuberance of playing trivia, I spotted Fernando striking odd poses and face when no one in the trivia group was looking at him.

> *And there it was in between the trivia questions, quick shifting, searching eyes, a smile that wasn't a smile on Fernando's face. Only the mouth smiled, but the eyes expressed pain. Exuberant laughter, juxtaposed by catatonic bodily stillness. I was gathering energy to go to the bathroom, as I saw Fernando scanning the room, looking to the hallway. I saw his face shift back-and-forth between a smile and distress. From the hallway someone entered the room, the bathroom was vacant again. When no one was looking I saw Fernando walk to the hallway, to the toilet. Closing the hallway door behind him, which has been open all evening. The urge for a toilet grew inside me. As I scanned the room for an opportunity, Fernando re-entered the room, whipped the sweat from his forehead and put a few mints in his mouth. He re-joined the trivia group, with much pompous, or energy, which was opposite of what I saw earlier. With a great smile he made everyone aware he was back and took his place. I saw his girlfriend look at him with eyes asking if he was okay. I saw him look away, deny feeling anything in the first place and dismissed the attention from his girlfriend. It followed with a joke and laughter with the man that stood next to him.*
>
> Excerpt Fieldwork diary, December 19th.

At that time it was unknown what Fernando's illness was. Though, when I went to the toilet after him, my recognition of his faces and distress was contextualized with the odours hanging in the toilet. Fernando had just vomited. His performance in the trivia group was made out of *mannerisms* (Ibid: 32) that would continue his healthy self, the laughter, exuberant body movements. In between, his backstage needed attention, the catatonic posture and face. Symptoms were revealing itself. Even his return connects to Goffman's (ibid.) use of attributes, the mints to mask his breath, the exuberant movement in returning to the group to make clear he was always okay. Dismissing the worries of his girlfriend worries, a lines with Goffman's (ibid: 141-142) thought on dark secrets that must not become known. Even the very clean toilet became the setting of a front stage, however the air-freshener failed to conceal the odour of sick to my experiences nose.

Not long after the Christmas dinner, Fernando reach-out to me and told me he had just been diagnosed with a severe case of Crohn's disease. He had fistulas growing in his small intestine, strictures with inflammation, which caused his food to find the other way out.

Discussing of a performances – post diagnosis.

During the months that followed, we had a continues conversation via WhatsApp, making it the third way through which I was communicating with him. This flexibility proved necessary as during these months we alternated between being 'sick' and 'sort-of-healthy'. We continued our conversation when we were able, where the script served as reminder where we left it. A consequence however, was the loss a context and embodiment as he would contemplate his answers in text. This loss however was a methodological necessity to continue fieldwork during toilet and hospital bound times for both me and Fernando. During these app-conversations, Fernando kept asking me questions about medical procedures and medicine. However, this changed as he started to share how he looked back at life and how he struggled dealing with his new way of experiencing live. He confessed concealing and downplaying his sickness and pain to co-workers, friends, family and even his girlfriend. He wanted to open-up and start the conversation now, instead of hiding, where fear of being *othered* made him silent before. Eventually these questions led back to Christmas. I asked him about the trivia, the toilet and the faces. He admitted all the observations even concluding 'After you left I was only able to maintain face for five minutes and went home. This validated observational data gives proving ground for the dramaturgical disability lens discusses in the theoretical framework.

Past this dramaturgical analyses, there also seems to a reflexive process going on. During the process of texting about living with IBD, Fernando kept coming back to a situation discussed earlier. He would change or add to the meaning of his experience. Receiving this new view on his life he admitted to 'feel less grounded in who I am'. Negotiating how he would act, feel and communicate about his sickness and his body in past, present and future situations, made him stressing out what he is or was. This could exemplify *narrative navigation* (Samuels, 2019) in IBD life narratives, as he places himself in a position where he can be loyal to many possible past, futures and presents of himself. However, the place of this negotiation, seemed reflexive, a process of making sense of the world, a sensitization tool for social situations. A process of him understanding his IBD-self.

Continuous Expectations: but who's are they?

This process of understanding once IBD-life is not rare among people with IBD. During small talks at a guided city tour in Haarlem, organised by *Crohn en Colitis NL,* I found a variety in how people with IBD started to re-make sense of themselves and their lives. During this guided tour I encountered Gloria, an Australian woman in her 50ties. She still finds it hard to meet new people: 'how should I compose myself. It is my illness, not theirs. They do not need to know why I am visiting the toilet so much.' At first she did not want to attend any activity with other people with IBD, but after her first activity she changed her mind: 'I expected to see only sick people, and I don't want to be associated with that. But that was not what I saw. Among these people, my people, it does not matter I have IBD. I can be at peace.' Gloria admitted that estimating what is expected of you, has helped her to live through social occasions, but when she is sick or feeling 'it', it is a heavy burden followed by social isolation and loss of friends. Although I was not able to observe how Gloria was able to maintain a healthy performance, discussing it revealed her great awareness of how to behave in social settings. Her awareness of how to perform appropriate *Region Behaviour* (Goffman, 1990[1959]: 109-110) has aided her across multiple *Regions* (ibid.).

Fernando's and Gloria's experience on trying to act healthy is a description given after I observed or asked them about it. But this theme of *playing an expected part* also resonates with discussions on online platforms. Unaware of the focus of this thesis, Daniel posted his experiences of having IBD and the mental struggles he faced before, during and after his attempt to re-enter societal participation through work after an extensive period of being sick. He posted the following text:

> *Sharing my frustration…. Since my last flare-up, tuberculosis and mental battle.. [I am] getting the things settled and straightened again these last few months. The TB is gone, the infliximab is doing its job again and no more side effects from Azathioprine and Mesalazine. I have reengaged with sports again, am paying more attention to my nutrition, and gained 12 kg in the last 2 months. I feel good and regained some confidence again.*
>
> *[This month] I applied for a job and last Monday I was on location for a shadow day. I found this to be quite exciting, naturally, moreover I was out and sick for months [and now stepping back in]. At the end of the day I had pain in my abdomen, in the same location where I always experience pain during flare-ups. That's why I call it 'my weak spot'. Luckily It was gone the next day.*
>
> *This does make me think again. Weird how that tension has so much influence on it. I am scared of this.. It makes me unsure about the future. Of course tension does decrease when you get used to something and you will start to feel comfortable. But how much damage do I do with stress and tension?*
>
> *As a man I sometimes feel like a poser. During the shadowing day everyone thought of me as relaxed and felt the calming effects I have on others. Inside however, very different things happen. My stress is almost as inconspicuous as I. Just as invisible as I sometimes feel to others. All my life I've been rarely seen. My talents are overlooked, but also my worries and*

> *stress. Everyone thinks I am a stable factor, someone who knows, who can do his business. Nobody ever asks me anything. Are you alright? How are you doing? During an interview the executive asked me what I am expecting from my team. I tend to say: 'Don't forget that I am here!' I have said this before on other jobs, but it always happens.*
>
> *I recently went to see a psychologist because of suicidal thoughts induced by losing my job due to IBD. This knowledgeable man who had my best interest at heart.. could not pierce my bubble. Simply because he had the impression that I am doing so well and have such a positive attitude. With everything I undertake and try to participate in society, my sense of perspective on it all. He did not know what else he could do for me. .But how do I live with this tension? How do I make sure that I don't always suffer from my stomach when I'm stressed? How can I be less bothered by my surroundings and all the idiocy? There, enough whining for a while.. Thank you for reading.*
>
> *[Translated from Dutch]*

Before I reached out the Daniel and followed the events in his life for two months, he posted his thoughts and experiences, demonstrating the interplay front and backstage of this thesis's theoretical framework. Furthermore, he discusses the medical and experienced ontologies of IBD through connections. Moreover, he lets us enter the backstage in his mind as he prepares for social participation.

In the first part, his recovery story connects with Goffman's (1990[1959]: 81,45) position on gaining and losing social position in western society. Daniel has cleaned himself up from his flare-up. However, in order to achieve this cleanliness, Daniel describes a rite of physical, mental and emotional activities. Through this rite he claims to himself and the world to be ready and free from IBD. Contradictory, he continues by contextualizing the pain he still feels and relates it with anxiety for the job interview. Paliswieskcs et al. (2016: 212) have placed the process of application as a classical dramaturgical stage in Goffman's view of front and back stages. But here we see him describing his pain before and after the interview, making the place of the interview, textually, painless. Van der Geest (2004:61) has connected the language of pain to the social surrounding and states the later to determines what and how pain is shared, or not. Daniel's weak spot can only be talked about before and past the interview, exemplifying the temporal agent of this expression. Though this shifting position, we can see how he feels the need to navigate his narrative of recovery (as fully recovered), with the paradox that to some degree he knows IBD will influence his next day.

Reflexivity on high expectations – behind the drama

Like Fernando and Gloria, Daniel places himself in a reflexive position answering and questioning a variety of effects related to social situations and his IBD and symptoms. Moreover, questioning the self he presents to his new co-workers. In this process he starts to negotiate between his body, IBD and the effects of the situation. But also addresses a temporal dimension as the effects are before, during and after present within him. The positive reactions on his calm façade, is juxtaposed to how he feels inside, back stage. He confesses that he wants to be less effected by his *surroundings* and the *idiocrasy*. This statement explains how the social environment is pressing expectations on to him. Expectations he physically cannot adhere to, due to his IBD and mental struggles. This brings a connection to Sevcik's (2014: 84) argument about raised levels of *anxiety*, *embarrassment* and *self-pity* in people with IBD. The origin of these raised levels is never discussed. But from Fernando's, Gloria's and Daniel reflexivity we can in infer a social construction plays an important part in how people should appear and behave.

After reading this message I reach out to Daniel and started to drink coffee together via Microsoft Teams and WhatsApp. These meetings were never short, but lasted hours, with many decaf-coffee cappuccinos. Followed by even more toilet breaks. For two months we had weekly conversations and whether he was sick or I, we stayed in contact through WhatsApp. As video calling from a bathroom or toilet was a no-go for us both, when one of us was *toilet-bound,* texting worked perfectly.

There is one particular conversation where we discussed, in-depth, what happens when he knows a social meeting, professional or pleasure, is coming up. Daniel started by telling how he emigrated from Greece as a some boy and had his first day at a Dutch preschool.

> '*Everyone was playing around, I was sitting quietly at the table. I was thinking that all these people will be in trouble soon. In Greece you must be quit before the day starts. But the teacher began and nothing happened. I felt free then, I wish I could feel that again. [..] This week I had my first real working day at the new location and although it all went well. I was sick the four days before. But Monday I was panicking, I could not sleep, stomach pain, visited the toilet 30+ times… I had a mild fever. Is this really happing, calling in sick on my first day. What should the think of me.'*
>
> Excerpt narrative Daniel.

After this I asked him what was going through him mind. 'Cant it be normal for once!' was his reply. When I asked him what normal was, he did not describe what normal is. He explained that he wants to participate, but that is also brings panic. He did the work, had muscles and stamina again. A silence followed.. He explained he went into alert-mode every time something social comes up. Four days before his first workday he already starts to feel tension in his mind and body. But also thinks about the expectations they may have of him.

Daniel at first did not see any connection between his mind and physical pain. Though later he started to wonder how his mind and body are freaking each other out. He described how hours before he went to work his mind was full and body was cramping up. He took a shower, a nap and a few painkillers. When he woke up, he went to work. He was sitting and waiting at the central office for someone to pick him, when he got into a conversation with the woman behind the counter. She admitted to have a little fever this night and was not feeling well. This had a disarming effect on Daniel, he told her that had been sick this night. Both were relieved, especially Daniel. He told me t helped him relax. When his new supervisor came to collect him, they were still talking about being sick. As he walked with the supervisor to the location, he asked Daniel if he was okay, good enough to work. 'Sick is sick, and it does not matter if it is your first day.' He told me this further disarmed him, but did not mention his IBD diagnosis.

After his first day at work, we drank coffee again and discussed how he felt. He still had cramps throughout the day. Only this morning when we woke up the pain was gone. However, his mind felt weird, he was calm the entire day at work. When I asked him why he did not mention his IBD he replied: 'I do not want other people to give it attention. If I would, it is very egotistical.' 'do you think it would help?' 'I do not know. I don't want people to look at me differently. If I were them, I would not know what to do with it. They are expecting me to do my job, perform professionally, not ask for attention with my IBD.' […] 'They are having high expectations of me, but also I expect myself to perform on them.' After this I asked him how he knew what their expectations were. Followed by a realisation: 'I have not asked them, but with all people I meet, or places I go... I make lists of what they are expecting from me, the highest expectations they have of me. It is how I would look at myself from their position.'

Connecting the dots

The connections between Fernando, Gloria and Daniel is seen most strongly in their ability to access the expectations of future social situations. In Fernando's narrative, I have seen the beginning of a continuous stream of questions, first medical followed by how to deal with IBD socially. In Gloria's description on how accessing expectations, has helped to compose and live through social situations. But also the fragility, as times of flare-ups leaves her deliberately isolated. In between, Daniel's realisation that he inscribes expectations to himself, by thinking about what other people should expect of him, exemplifies that even in periods when IBD is less active, the reflexivity on how to perform a healthy-self continuous. Across these narratives, different experiences of social awareness and use of dramaturgical appearance, mannerism and setting (Goffman, 1990[1959]: 32,34,29), demonstrate the ease or struggle people with IBD have in maintain the arts of presenting a 'healthy-self' and managing their 'sick-self'.

4.2 Elisabeth and her son.

As the previous narratives sketched out different how people with IBD manage their sick and healthy self, this paragraph explores how people around people with IBD are effected by IBD. Specifically the perspective from Elisabeth. Her son was diagnosed with IBD on a young age. Here story and experiences with and about her son demonstrate how IBD has influenced her relationship with her son.

Small streets, good conversations

I met Elisabeth on a cloudy Saturday morning. We both were attending a city tour organised by the national IBD patient organisation. The group gathered at the train station and as soon as everyone arrived we hiked into the city and its many small streets. This made it a cosy walk, but also one where you could hear what the others were talking about. I was the only one who came alone, others came with a spouse, family or friends. This made it possible for me to have small talk with many members of the group. Eventually I started talking to Elisabeth, who brought her son along, now seventeen years old. Although Elisabeth was not walking with her son, because he brought a friend, somehow there was an immediate connection between me and her. I told her about my years of sickness and troubles with gastroenterologists and we connected on this, but there was more. As she asked me how my network was coping with these years, I told her I am an orphan. This resonated as she just took in a young girl left on the streets by her father.

We continued the walk together, admiring the city and asking questions back and forth about IBD and life. Eventually I told her about my research into IBD and how people reveal and conceal it from others, but also the impact it has on the relationships you have. Without hesitation, she started to tell me parts of her son's story. He was diagnosed at ten and has been fighting for eight years with Crohn's disease. But this fight was not just his own. Between the lines of her son's story, she would mention her own fight and role as a mother in supporting and guiding her son through it all. After the walk, we stayed in touch through WhatsApp. I wanted to plan a family interview with her, but sadly enough my own recovery was slowing down and I needed surgery. Thus, I asked Elisabeth if she would write down the story of her son, of her family.

In the period that followed I was struggling with my energy levels again. But reassuringly enough, Elisabeth and all the other interlocutors recognized what I was going through. No explanation was needed and text messages continued daily or weekly. Back-and-forth communication continued

Eventually Elisabeth wrote to me: ‘It all started on Thursday the 10th of September, the rollercoaster of the medical mill. ‘They are suspecting Crohn’s disease….BOEM’. Her expression of a bomb being dropped with no explanation. The pathological symptoms of her son began early on. He experienced constipation, abdominal pain when he was younger. During the summer before he was diagnosed with two rectal abscesses, which now developed into fistulas. From a diagnosis made by the GP on September 9th, they found themselves on the 10th visiting a paediatrician. Followed up by appointments for MRI, bloodwork, faecal analysis, consultations with a surgeon and following up with surgery and a colonoscopy.

His expressive symptoms during the summer were not limited to pain. He was unable to sit, stand or walk. ‘The only thing he could do with limited pain was lay on his belly. But going to the bathroom [for pooping] was a disaster.’ Elisabeth's experience of their talk with the paediatrician was overwhelming. ‘He started asking all kinds of questions, they needed to weigh him, measure his lengths. Suddenly, he was too short and too skinny for his age. They asked about the family's medical history. ‘My son’s grandfather was diagnosed with Crohn’s. ‘ she uttered.’

The week after Elisabeth and her son would visit the hospital every day for examinations or receive phone calls with results. The panic was raised as they heard her son’s CalPro was 1500 instead of <50 (the marker for inflammation related protein, see theoretic framework). Both not understanding, but having anxiety for what was going to happen. The colonic irrigation before surgery was the worst. Her son kept vomiting the fluid for hours, instead of digesting it.. He needed to stay in the hospital that night and a stretcher was placed next to her son’s bed.

The next day she and her son were brought to the surgery ward and after her son was given the narcosis and fell asleep, the first tears started to flow. ‘After an half an hour I walked to the shop and bought the biggest minion balloon I could find. After a while my husband joined me, just before my son came back from the OR. I can still see the pearls of sweat in his neck. He opened his eyes, locked on me, and fell asleep again. After an afternoon of nausea and continuous puking. We could go home, with 30 bottles of medical nutrition. The first step of his treatment.’

Rites, initiation and change roles of parents.

In anthropology many scholars have written about rites, initiations and rituals through which one is gaining excess to a group, adulthood, ect.. More specifically, Driessen (2002) work on pain and culture describes cultural rites across the civilisations of the world that involve chosen pain as an essential part of achieving or maintaining a social status. He describes rites for adulthood, feminine rituals of puberty, but also how muscular pain is a central part of athletic lifestyle or a career in the performative arts (ibid: 47,73, 123, 135). However, Driessen's (ibid.) approach to pain through illness is limited to being a consequence of a medical reality. I therefore would like to supplant this discourse by introducing 'IBD-rites' of initiation and regaining health. The 'IBD-initiation', as described by Elisabeth, is exemplary for people with IBD. Similar to Fernando's experience a period of undiagnosed sickness is followed by a quick medical experience of diagnosis.

The role of the parent also changes within this IBD-initiation. During fieldwork I attended an online group meeting for parents with children with IBD. Here I met twelve parents. Most were very new to the reality of a child with IBD (the first week or month after diagnosis). Two of them had children who were coping with IBD for years. In this meeting the 'lonesome' position of parents was shared strongly through discussing medical topics (nutrition, medication, examinations) and social symptoms (children being 'socially and emotionally exhausted). Yet, in relation to themselves, many of them become puzzled about how to prepare their child for adulthood, while they also have to manage IBD. Another question was how to deal with a child that was getting socially isolated by being absent. Through fatigue or pain, parents observed social activity to be diminishing. More painfully, three children were being ostracised at school for being away for a long time. Revealing their sickness did not end this: *'children can be so hard, when you have something, or be different from others. They will make you feel it.'*

All parents shared their stories on how their child needed to undergo the standard physical examinations, *'drink two litres of laxative, that tastes horrible. [..] standing by my child as the colonic irrigation starts.'* While the 'experienced' tried to comfortably share the realism: *'This will not be the last time! Trust me on that!'*

Many of them reflected on my question: 'In what ways did your parental role change?', through the example of a 'carte blanche'. *'I have two children, but one of them receives almost all my attention, no matter what. I will do anything to make his life as normal as possible. Even when he is grown up, I will always worry about him.'*

At the end of the three hour meeting, all parents spoke out of gratitude for getting recognition for the pain and struggles they had. Moreover, many of them lost the feeling of being alone in this and wanted to connect and have a regularity in meeting up and sharing. All of them were then accepted into an online forum for parents of children with IBD.

Both these parental stories are revealing the reality versus the creation of the social construct of IBD within a family structure. Likewise to the hypothesis in the theoretical framework of pathological, expressive symptoms and social symptoms. IBD transposes from pathological symptoms explained by doctors, through expressive symptoms seen in your child. Here however it also transposes to the 'parental front stage' of supporting and taking care of your child. Parents implore mannerisms (Goffman, 1990[1959]: 32) to strengthen their appearance (Ibid.: 34) and be seen as strong and dependable by their child. Only given themselves a backstage break:

> *‘My shoulders have not always been strong enough. It is okay to cry, the diagnoses, surgery, worries about the future. Showing my tears to my friend is so necessary. But the real fits of crying came underneath the shower, putting on some loud music and letting the tears roll. It brings relief, for a moment.’ –Elisabeth – March 2023*

Through these questions and revelations these parents are redefining their role as parents. They are part of the medical and social change that follows after diagnosis. Although Goffman (ibid: 85) has defined performance teams as a collaboration of individuals in a single routine, the position of the parent as revealed above demonstrate this to be false. Parents become other performers on the stage of IBD-life. As exemplified above, they conceal their emotions and express them only in a un-intrusive backstage (ibid.: 114-116). Elisabeth only allows herself tears when her son is not watching. It has become her dark secret (ibid.: 141-142).

Traumatised family – IBD consequences for the network

However, the compatibility of Elizabeth’s story to others stopped here. After a month of exclusive enteral nutrition (liquid medical nutrition), her son needed to undergo another colonoscopy to evaluate the process of tissue healing and remission of Crohn’s disease. Though she thought she knew what to expect, ‘it was horror, really.’’

> *‘Again my son received a nasogastric tube and two litres of laxative fluid began pouring into his stomach. But this time everything that went in, he vomited out. Somewhere during the night it started working on his gut and irrigation began. He was sitting on the toilet with cardboard spittoons. All the pyjama’s we took with us were used up before the morning. He was brought to the x-ray department in his underwear and blankets. Beth, the pedagogical employee, also joined us. Just like the first time. But then… the doctor needed to put a nasogastric tube through the stomach into the small intestine to do the examination. I saw the fear in my son’s eyes growing, panic rising. We tried to talk him through it, and brought out the motivational gift bag. But it became a fight, me, Beth and the nurses had to restrain him to the table. Pushing him down and holding him still. A horror fight, while he was crying. All these examinations, blood tests, something snapped in him. In raging panic, he ran out of the examination room, to the elevators, afraid, it was done ’*

In all honesty, reading this story brought tears to my eyes. I will not know the full extent of his fear, but I could empathize with him, as also I was restrained on a table while being examined. For Elizabeth, telling this story still brings tears to her eyes. She and her son received therapy to cope with what had happened. For a long time her son received EMDR therapy for the trauma that was in his mind, and body. Even Beth received therapy for this experience and the hospital altered their procedures to prevent this from ever happening again.

In the years that followed Elizabeth's son struggled heavily with the consequences of IBD. Though he received medicine, the inflammation activity remained. More often, he was at home exhausted, in pain. Often he had to return to the hospital to treat constipation. When he did attend school, he was exhausted within the hour. '*His classmates and teachers did not understand this. He received a map with drawing and well wishes. Yet, only a few of his friends visited, once. A grown-up life-lesson no child should learn.*'

Explaining IBD to children – Decisions of disclosure

A dramaturgical approach on school life could deepen our understanding of what is front stage knowledge and what is not, or how IBD causes social isolation. Elisabeth's son also needed to prepare a presentation ('spreekbeurt'in Dutch), and they transposed living with IBD into a 'spoon-theory'. The theory is very simple. At the beginning of the day you'll receive twelve spoons. Every activity you do costs one spoon. See also the image on the right.

> *'In front of the class you told them you have Crohn's and this also means mood swings, depressive thoughts. 'A small tease can have big consequences for me. This is why I can be down at times.' After [explaining] this [to everyone], the children were more understanding, just as the teacher. No longer were they looking at you when you went home in the afternoon, or did not join in on PT*.' – Elisabeth memorizing her son's presentation.

To some degree Elisabeth's son revealed a big part of his backstage to his classmates and teachers. A strategic secret of revealing what happens internally. The purpose of this strategy could have been gaining understanding for his situation. The spoons were instruments to make an un-relatable disease relatable through the costs of living activities. In Elisabeth's son's case this strategy worked, as the awkwardness left the situation.

However, this strategy also revealed new boundaries and limitations, certain information remained classified. The amount of hospital visits, rectal enemas against constipation, ergo what happens on the toilet, was not discussed in front of the class. The stage of the presentation was still instrumental as the performers decided what to discuss, where to look at and what not to speak about. Whether this is to avoid stigmatization or taboos remained unclear. I chose not to ask these questions as to me it seems unethical to revisit this situation and relive these trauma's for child and mother.

The mother's perspective and online forum sharing

> *'Luckily, I am someone who knows how to keep herself strong and standing. Because, jeez,.. This all had a large impact on our lives. The continuous care for your children influences everything. It was not only caring for my son. When his IBD was calm, my daughter was diagnosed with autism spectrum syndrome. It was as if they were taking turns for my attention.*

Thus far I have explored the impact of IBD on the social structure of a family, exemplified how relations change and what masks are being constructed in the name of love and care. But IBD's contamination into social structures does not end here. As mentioned earlier, the child's relations to its peers change though the temporality of illness and the ostracising effect of otherness. When I asked Elisabeth about her extended family and friendships, she replied:

> *'all of them were under pressure! We could plan something very enthusiastically, but had to cancel at the last minute as another surprise hospital visit interrupted our lives. I have lost many friends to this, moreover there is more distance between me and my extended family now.' – Text message Elisabeth march 2023*

This out-reaching effect of IBD in social structures may differ from case to case, but in fieldwork I found more people talking about a shrink in social network, social contacts and support relations. Caroline, a woman I met during a real-life gathering, told me that she had just moved to the Netherlands from Australia, had built a network of people around her and her husband, when she fell ill of Ulcerative Colitis. Many of her new friends were lost due to the presence of uncertainty of attending birthdays, or celebrations. Friends told her they found it hard that she was not there when a child was born. Though this research did not go into this field of study. To me it seems like people walking out of a theatre, because the show took a disapproving turn. Whatever the reasons, it hints at the far reaching consequences of the IBD diagnosis.

The mother carries on - narrative navigation.

> *'I have carried all his fears, pain and saw his sadness, carrying them as a rock in my stomach. These things really tear you apart as a mother. [...] Father and daughter at home, mother and son in hospital, it was difficult for everyone. [..] Even when we were home I was constantly thinking, is this a Crohn-stomach-ache, constipation, side-effects from medication, or stress from taking the nauseating medication?' – Elisabeth – March 2023*

Though Elizabeth would never show her worries to her son, this quotation shows another dimension of a dramaturgical backstage. The backstage of analysing her audience to plan and foresee interventions. Later, she told me that this position came to her out of fear. She doubted every symptom and always was trying to see what was going on inside of her son.. But in the same sentence she was telling me how open and close her family became through this. Struggle could bring people together, but also drive them apart. In Elizabeth's case we can see both. Here she remains loyal to both her singular fear and the loyalty of being a strong and open family 'where we could talk about everything.' Moreover, the more we started talking about the experiences here in a helicopter view, the more she tried to navigate the loyalties she felt, and possible futures. While discussing losing position as a host family for troubled children, she spread her loyalty between her son's needs, her own need to take a step back, while also explaining it to be the right choice for the children she hosted. This spread out loyalty was then framed by the position 'As mother, you will always put your child's pain, sadness above your own. you'll go into a survival mode'. Here she is keeping open the possible future of the host family once more and her 'naturalistic' expectation of motherhood.

Online, However, Elisabeth found support by sharing her experiences in hospitals with all who were on the forum. Every time she went to the hospital, or was wondering whether a treatment or medicine was familiar, she posted a message on the forum. Eventually Elisabeth shared all her posts with me, from the first year, to the last one. Where her son received his driver license. Though not an IBD experience, it is a life experience. Due to anonymization falling short in sharing online posts here, analysing these posts revealed two positions, or reasons for posting. First there is the one mentioned above, sharing and asking questions. The other reason is what happened after the post was outed. People whom she never met, sending supportive messages. Follow-up with emoji's and messages as Elisabeth updates the situation of her and her son in the hospital. Through these posts, it seemed as if the diagnosis and ongoing treatments were carried by more than just her. But with people who could empathize with her situation. In more messages, she responded with 'thank you very much for the support this day.'

The online world is a stereotype for non-physical front and back stages. The role and function of this forum may serve both places simultaneously. The difference between people drawing attention or the need for support, cannot be observed in the words they use. Though in Elisabeth's case, it became a place to gain reference for the reality in medical terms and in social terms, through being part of a group and finding recognition in posts that others shared. The topical analysis of this platform demonstrates this duality of medical and social themes. The fast majority of posts are questions about medicine, treatment and questions if anyone has experience with them. Furthermore, it is also a place where pathological and expressive symptoms are being shared. Also here people ask if anyone recognizes certain symptoms, often including a photograph. But to recap the narrative of Daniel, people also share their social symptoms and struggles that transposes past their own experience of IBD into their social relations.

The core exploration of this thesis is how IBD becomes a social entity and influences the meaning of communication and relations. Through the eyes of motherhood I have explored how the reach of IBD is not limited to the person who is diagnosed, but strongly influences the creation and maintaining extended relations and social network. By using a dramaturgical approach as an analytical tool it has revealed how IBD creates performers of family members, concealing emotions backstage. Even future back stages

> *'Now my son is eighteen and I see a social, independent young man. He is making friendships, trying an education and has a job. These life lessons were hard, but somewhere necessary. Though I will keep my fingers crossed and hope it will remain this way as long as possible.' – Elisabeth -2023*

4.0 Conclusion

The narratives of Fernando, Daniel and Elisabeth have exemplified how IBD goes from a medical diagnosis to a social entity that influences how they communicate to others about being healthy or being ill. From these examples I will now answer the questions I was set out to investigate. *'How do people with inflammatory bowel disease manage their presentation of 'healthy-self' and 'sick-self' in everyday possibly stigmatised life?'*

4.1 Management of 'sick' and 'healthy' self to people without IBD

The mastery of self-presentation with IBD is not a given skill acquired during diagnosis. Evaluation of oneself(body and mind) and the surroundings(audience and setting) has demonstrated to play a continuous role in how people are allowed to see you and how you see yourself. In Fernando's case it led to many questions on the management of the illness and learning a new way to be honest and open about it to others and himself. Daniel's struggle with social expectations of others and his own, demonstrates the reflexive process continues after a period of sickness. In Elisabeth's relation with her son has changed. She is scanning for any sign of IBD in her son. While concealing her emotions and perform a dependable parent as front.

The self-awareness bootstrap – Reflexivity gone wild

Fernando narrative was very explicit about the questions he asked me when he received the IBD diagnosis. These questions were all about how to deal with IBD in a medical or social sense. These were his first steps on his path to a new awareness. In Daniel had a few years of experience with IBD in everyday life, but still copes with social situations by himself 'what do people expect of me? And how can I not look ill, sick or weak?' He is maybe further down the path chronologically, but still questions every step he takes in social life. Elisabeth, though not diagnosed with IBD demonstrated a similar route, as she continuously is scanning, asking and observing her son's behaviour to estimate whether he is having symptoms or experienced something on the street or at school.

All these stories contain a process of developing self-awareness in relation to an audience. Which leads to questioning the world around them before making any choice or taking any step. This awareness had taught them how to survive social situations or minimize status loss. Questioning every step is therefore essential to the management of ill and healthy self. But it is also a bootstrap. The skill is developed to walk the path of life and answer the questions that come from it. But is also feeds back into the social adaptability, making them more adaptable, more self-aware while comparing to the other. Moving away from the ill-self that will not change and the healthy self to will change according to the audience.

This management opens up the doors to self-stigmatisation and mental dismemberment of their physical IBD entity. Making them address themselves as dirty as they expect others to think about them.

'When we are together, it's okay!' Also online.

This quote came from the person sitting next to me, while drinking a coffee after a guided city tour for people with IBD. It summarises a pivotal point from an interactional viewpoint, but also summarizes the fieldwork. The process of questioning, finding your way through taboo and stigma filled social life, felt lifted in contact with other people with IBD. During all the meetings there was a process of identification that involved your name, followed by IBD type. But this initiation to the group you could speak to others as if they were friends, family or kin. A sense of kinship was felt in all groups through common troubles (symptomatically and social) all derived from living with IBD.

The two years before fieldwork started, being sick was a lonely experiences as none could truly understand what I felt or how I had to deal with it. In total I attended 10 meetings, met over 100 people with Crohn's disease or Ulcerative Colitis, every single one I saw for the first time in my life. Remarkably, a familiarity was felt between all of us. Whether is was the group conversation after a yoga class especially for people with IBD or an online discussion group, after the identification through IBD subtypes, people began to talk to one another. Discussing how often they visit the toilet, how often they lose blood, need a hospital or cope with an employer that doesn't want to understand the meaning of being sick. This togetherness can also been seen in the posts shared in the online forum. Similar life domain are topics of discussion and supported by all who want to share and respond. Though this thesis is limited by a topic analyses only. Investigating the online interaction of the posts would also be a rich soil to see how taboos and stigmas are lifted in online communication.

4.2 General conclusion

From the onset, this thesis explored where the medical and pathological nature of IBD stopped and where social influence was felt. This discrepancy can also be read between the lines of both conclusions above. The individual management and its bootstrap is separated from the medical experiences and often causes a behavioural spasm of 'act normal'. Whereas the communal experiences does the opposite, 'you are normal and its okay.' In the ideal world patients whom receive the diagnosis should actively be made aware of the IBD community. Though it is a personal choice to join, in all the people I have met it evoked a social healing in representation the ill-self. My hope and activism goes out to re-valuing patient experiences in the medical *modus operandi.* Hereby possibly preventing the self-awareness bootstrap.

4.3 Discussion

As discussed in the theoretical framework and positionality, my position as researcher and fellow patient is quite new in anthropology when it comes IBD. Although not part of the themes and questions of this thesis, I do feel motivated to include a retrospect and conclusion on how my entanglement has played out.

Entangled Positionality and Personal Growth

During the writing of the fieldwork diary and writing this thesis, I purposefully have written about the health problems I was facing during the fieldwork. Also when describing the narratives in this thesis I used inserts as a place to make the reader aware about the position I was in. In my hope this makes clear how the insider effect was not only limited to have experienced similar health problems, but so demonstrate the context through I was able reach-out to the interlocutors. Or make clear the reasons why modes of communications changed overtime. During fieldwork modes of communication changed not only because I was receiving treatment, but also because some of my interlocutors where getting sick. Investigating interactions of people with IBD is thus not only reflecting on or observing situations, but also a multi-modal method of ethnography as written texts, physical conversation and online meetings are interchanged by the possibility of the sick ethnographer or the sick interlocutor.

A second argument for discussion a personal development while being in contact with other people with IBD. Many of my peers have come back from exotic places in the world, awestruck by what they have seen or the overwhelming return to life in Leiden. In a similar way like them, I was awestruck by the people I met and walked with for the four months of fieldwork. Before this fieldwork I experienced having IBD as a lonesome illness through the social isolation it brought on me. The loss of contact with friends and family was a personal difficulty I could not change. Yet, this study made lose that lonesome position as I found a kinship in people I would have never met if it was not for this thesis and fieldwork. In a sense the theoretical entanglement of an ethnographer to its research field by Ginsburg & Rapp (2013b) has entangled me to a group of people whom I now feel a kinship to. Although it a personal development, future research into how this kinship develops between people with similar medical diagnosis would be a new focus for a disability lens (Ibid: 52,62).

Analytical Methodological discussion

In the theoretical framework I discussed how Goffman's dramaturgical approach (1990[1959]) was based on observations made in a hospital over a long period of time. This thesis, though the period of my sickness was two and a half years, is strongly limited in time. I therefore need to address to what degree Goffman’s framework as an behavioural analytic tool was effective. For this I will focus on the narratives described and the analytical applied to them.

In the narratives of Fernando, Daniel and Elisabeth the dramaturgical approach was an efficient tool to explore how a stage can be both a front and a back stage simultaneously. For example, Elisabeth’s presentation on school. They revealed information, but also held back a lot of the reality of a life with IBD. Mainly, taboos about poop, blood and enemas, which could lead to stigmatization of her son. ‘*as children can be so gruel..’ -Elisabeth-.* The strict defined lines between front and backstage as describes by Goffman, so not always seem to apply to people with IBD. Here, the revealing is strategically dosed, revealing limited information every time. Another example can be found in Daniel’s first day at his new job and his nausea. Or Fernando’s truth when he confessed to have mental problems with accepting his new life. Though this may seem to work against the efficiency of Goffman’s approach. It actually supplied a clear view on how the backstage keeps changing. As if in a state of flux. With the disseminating analyses of dramaturgy, this state of flux would not have become visible.

The use of Goffman’s dramaturgical approach to follow the path through which a medical condition becomes an influencer of social constructs, has demonstrated its ability to differentiate between thoughts and symptoms, but also the how front and back stages travel and change in relation to what is known about a person’s IBD. I strongly conclude the use of the dramaturgical approach to be instrumental to find how stigma and taboos are constantly avoided in social interaction.

Ethical awareness in the field.

During fieldwork I encountered a ‘uniqueness’ in every story. A lot of it took place in social situations and opened doors to a social complexity that was different from my own. In practise this led to me telling my interlocutors about how I interpreted their story. Which was always nuanced as my own frame of reference did not comprehend or in line with their experiences. Furthermore, in writing the narratives, my interlocutors made me aware to the sensitivity of specific words in writing their story. These other frames of references opened up the reflexivity in not playing into self-advocacy or self-serving-biases, by finding the difference between us. Representing the other(ness) remained functionally paramount.

There is however one situation where the potential for harm was,.. tangible. One of my interlocutors, a mother of a child with IBD, wanted to tell me her story. This story was filled with traumatic experiences. At one point she acknowledge reliving the experiences, at night in dreams. Which was hard for her and not without tears. The need to share the story was stronger than the avoidance of reliving traumatic experiences. This motivation from her side pinned me to my chair/screen, uttering ‘I will listen to what you want to share. You should decide where we go! As mentioned before I was aware of the feedback loop of vulnerability, but I did not see this vulnerability. Although she decided what to tell me, there is no harm in listening, I still find it difficult differentiate whether it was ethically sound to do so. Although she was in control, afterwards I encountered an ethical pitfall through my own entanglement with IBD reality. I could emphatically feel her experiences through my own experiences. With respect to her story will use it for this thesis and she wants me to exemplify it. However, I still feel I have asked too much.

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