Responding to Biographical Disruption: Navigating Strangeness and Belonging After Health Disruption

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Abstract

This thesis aims to explore the implications of biographical disruption, which relates to a drastic (and often unexpected) life change that is framed as a health crisis and is caused by chronic illness or an acquired physical disability. At the centre of this thesis are questions about belonging and strangeness negotiation as people with acquired disabilities or chronic illness navigate the transitions they experience.

Informed by a pilot study conducted in New Zealand, the research is based on data collected with eight Israeli participants who experienced health disruptions and were interviewed multiple times. Their narratives were the basis for understanding intersectional processes that are triggered by reconstruction of a sense of control and safety during belonging negotiation. By using a constructionist epistemology and narrative analysis methodology, the research unpacks the participants’ interpretations about their experience of biographical disruption.

Participants’ narratives revealed the challenges they coped with when renegotiating their belonging and strangeness after a life changing event. As active social actors they were able to utilise their agency to reconstruct a sense of control and safety during belonging negotiation, and that impacted the choices they made during self-identity construction. The research offers the control–safety–choice (CSC) model to address the conditions that are required for both belonging and strangeness negotiation. An important facet of this process is the intersectional aspect that is related to mobilisation of chosen intersectional identities during belonging and/or strangeness negotiation, and thereby impacts self-identity construction. By exposing the mechanisms that are involved in the process of self-identity construction on a belonging–strangeness axis, the research aims to identify the participants’ agency during their journeys.
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This project would not have been completed without my mother who supported me throughout it and my entire life, and my father who was there for me when I needed him.

This research gave me the opportunity to experience a life-changing event, and from that to craft the meaning about negotiation of belonging and strangeness. I had the privilege to hear the stories of individuals who coped with biographical disruption, body change and different challenges and hurdles, and understand from them about acculturation in general, and my own in particular. Their narratives are this thesis. Without their time, effort, and contribution of their interpretations I would have not been able to complete this research and my gratitude is forever theirs.

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This thesis is dedicated to my late uncle, Yishay, who passed away during my stay in New Zealand, and believed in me beforehand and always.
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Chapter 1: Introduction

This thesis focuses on the meanings that individuals conceptualize about their experiences after a significant health disruption. A life changing event can undermine assumptions about the world and about the self (Janoff-Bulman, 1989) and set challenges in constructing self-identity as before a disruptive event. Such drastic event, then, can reveal the conditions that are required for belonging and strangeness negotiation. A significant change in life can undermine a “taken-for-granted” sense of belonging (Yuval-Davis, 2007), which leads social actors to actively renegotiate their belonging and strangeness with both new and original social circles.

This research is based on Bury’s (1982) biographical disruption theory that was developed out of his work with a different type of health disruption event of chronically ill individuals. As will be discussed along this thesis, for this reason it would have been adequate to focus on disruptive events such as chronic illness. However, at an early stage it was clear that an acquired physical disability would be a better focus for this research. Having said that, this research did not exclude chronic illness form its samples and theoretical framing and instead, refers to a disruptive event as a “health disruption” that is a life changing event that involves a significant physical crisis. The main reason for such a conceptual framework is that some of the participants in this research developed disabling physical symptoms as a result of chronic illnesses (such as arthritis, MS) and an analytical boundary between their experiences of chronic illness and acquired physical disabilities was not possible to draw. However, at its core, the conceptual framing of chronic illness and acquired physical disability as "health disruption" encapsulates a profound shift in perspective. This framing transcends mere medical terminology, delving into the intricate interplay between identity, belonging, and the innate human response to life-altering circumstances. By viewing such conditions as disruptions to health, rather than mere medical diagnoses, this thesis highlight the transformative nature of these experiences. This lens places emphasis on the meaningful impact they have on one's sense of self, relationships, and place within the world. It acknowledges the nuanced renegotiation of belonging that occurs as individuals navigate the uncharted territory of their changed reality.

Physical disabilities that are resulted by injury or chronic illness, as will be demonstrated along this thesis, lead to a significant life change in individuals’ lives. For example, both type of health disruptions impact individuals and their families, and all have to accommodate to the changes made. They may cope with a stigma, for instance, that complicates belonging negotiation after a disruptive event. Therefore,
the interpretations and meaning making of self-identity construction after a health disruption was at the focus of this research, rather than the homogeneity of the reasons that led to a life changing event. In other words, this research’s focus is on meaning-making processes in negotiating strangeness and belonging after a health disruption, rather than the cause of participants’ acquired disability. The narratives that will be presented later will elaborate upon and justify the inclusion of both groups in the same analytical frame of health disruption.

A pilot study that took place in New Zealand helped to orient and deepen my research questions with people with an acquired physical disability, which explored the initial and overarching questions that this thesis include:

- How do people renegotiate their belonging (and, relatedly, strangeness) after a health disruption?
- And how does that impact their self-identity construction?

From these experiences, I reshaped the research question for the main study, conducted in Israel:

**What conditions are required for belonging and/or strangeness negotiation during disruptive events?**

The New Zealand pilot study was utilised to develop the main research that was conducted in Israel. Although this research is based on a number of participants from both countries, it is relevant to a large portion of the world population: according to the World Health Organization (2011) approximately 15% of the world’s population lived in 2011 with some form of disability. As such, the particular statistics from New Zealand and Israel may be relevant to even a larger number of people in the world. For example, in 2013, 24% of New Zealanders identified as people with disabilities (Stats NZ, 2014). Israel's Commission for Equal Rights of Persons with Disabilities (2020) indicates that in 2019 20% of the population lived with a disability. Only 35% of Israelis with severe disability were employed before the Covid-19 pandemic, 46% of whom did not hold High-School Certificate, and almost third of whom reported experiencing high levels of stress and sleeping disorders. Living with an acquired physical disability means becoming part of these presented statistics. One’s well-being is jeopardised and thereby individuals become more vulnerable, and in some cases experience biographical disruption, as will be detailed later in this chapter.
This points to the potential relevance of this thesis to many people around the world that experience a health disruption. Acquiring a significant physical disability is an event that many people around the world may experience; however, they do so according to local cultural conventions. For example, some experience stigmatisation and other events in which their identity is devalued, while others are granted with the opportunities to be empowered by the physical changes their body experiences. The concept of health disruption holds a universal quality, as it remains an event that can transpire in the lives of anyone, irrespective of background or circumstance. This significant life shift, while rooted in the realm of health, has the potential to touch each of us in some capacity throughout our life journeys. However, it is crucial to recognize that health disruption is just one exemplar among the myriad of life-altering occurrences, especially those entwined with physical facets that individuals may encounter.

In this light, the notion of renegotiating belonging takes on a broader relevance, extending its significance to a multitude of people across the globe. The intricacies of redefining one's sense of belonging and grappling with the unfamiliar can resonate beyond the confines of health disruptions alone. Diverse life-changing events, whether stemming from health challenges, unforeseen circumstances, or personal transformations, have the power to propel individuals into a state of revaluation and adaptation. Not all disabilities are acquired during adulthood, as with the experiences of the participants in this research; however, a life story that involves physical disability can meet at mutual intersections, such as empowerment, stigma, devaluation or a problematised belonging negotiation process. This thesis is focusing on Jewish Israeli participants and therefore cannot reflect the experiences of Arabs in Israel, for example.

This thesis is based on an intimate micro level research that was conducted to explore individuals’ interpretations of their journey with a significant acquired physical disability. As such, it aims to understand subjective constructs that are reflected in individuals’ narratives, as it assumes that individuals’ interpretations and meaning development can shed light on experiences in which one’s self-identity cannot be constructed as before. However, from this intimate, narrative-focused level this research unpacks general ideas that are related to individuals that experience disruptive events in other contexts.

As mentioned before, this research is based on individuals’ constructions and interpretations, rather than objective reflections of events. As such, it does not aim to describe an unbiased reality, but rather the process of meaning making and self-identity construction as it is reflected by the participants’
narratives. These methodologies were selected as this research’s epistemology relies on constructionist principles. Therefore, it emphasises the importance of social actors’ constructions of meanings and interpretations indicates that biographical disruption is culturally bounded. I unpack the complexities of this claim in the next chapter.

The process of belonging and strangeness renegotiation during and after health disruption can provide valuable knowledge about self-identity construction. However, such examination would not be complete without the intersectional awareness that considers how the experiences of belonging and strangeness negotiation provoke, sustain and create identities. In other words, the intersections between one’s multiple intersectional identities and intersectional aspects of “the other” would trigger belonging or strangeness negotiation. Multiple intersectional identities are available (or not) to social actors during interactions with other social actors. The performance of different identities that reflect social actors’ belonging and strangers, will also impact the process of belonging and strangeness negotiation.

It is important to emphasise that due to the scope of a PhD dissertation it would not have been possible to take into account all the intersectional identities of the participants. In essence, this research adopts an intracategorical focus of intersectionality by concentrating on the identities linked to health disruption with participants’ intimate social networks and familial roles. Thus, this deliberately focused intracategorical approach hones in on dynamics that hold paramount significance in the participants' meaning-making processes. While the critique of the medical model involves referencing structures and macro-level power dynamics (see Chapter 5), the study’s primary emphasis is directed towards the micro-level aspects, grounded in recognizing the complex interplay of diverse identities and their collective impact on health disruption.

An analogous micro-level examination of intersectional identities in health research was conducted by Gabbidon and colleagues (2022) in their exploration of the experiences of youth living with HIV. They employed intersectionality as part of an integrated framework to develop a ‘Process Person Context Time Model’. They argue that HIV particularly impacts vulnerable population groups, whose intersectional identities create ‘intersecting stigmas’, necessitating intersectionality in analysis. Using Bronfenbrenner’s ecological model as a starting point, their research focuses on the proximal processes and relationships experienced – at the micro-level – by the young people themselves. Likewise, the intracategorical emphasis in this research's intersectionality analysis resonates with participants’
subjective viewpoints, giving precedence to the significance they assign to their experiences. This focus enhances the theoretical robustness of the research and ensures practical relevance. While most intersectional analyses typically trace societal and institutional structures perpetuating inequality, this research contends that engaging with individuals' meaning-making around their intersectional and intracategorical identities within the micro and proximal realm is also valid and valuable, as highlighted by Gabbidon et al. (2022).

In a similar sense, Lindley et al. (2020) provide valuable insights into the dynamic interplay between various levels of the eco-developmental framework and their intersection with gender and sexual identity construction among transgenders. Their exploration of micro, meso, and macro-level influences highlights the intricate interactions and conflicts that shape individuals' experiences during significant identity transitions within their interpersonal social contexts. At the micro level, their research delves into the personal experiences of transgender individuals, including aspects such as embodiment, interactions with intimate partners, and feelings of acceptance within society. They examine how individuals navigate their gender and sexual identities on a personal level, including the challenges and conflicts they encounter. By delving into the complexities of these ideas, the researchers emphasize the nuanced nature of identity development processes, recognizing the diverse and multifaceted experiences that individuals navigate. Moreover, their findings underscore the importance of adopting an intersectional lens to understand the intersecting factors that contribute to gender and sexual identity construction, enriching our understanding of the complexities inherent in identity formation journeys.

It is essential to underscore that although the focus of this research and others diverges from mainstream intersectional scholarship, it holds significance and has a legitimate place in intersectional perspectives. While traditional intersectional analyses often centre the critique of social structures and institutional systems perpetuating inequalities, this study, guided by an intersectional lens, takes a somewhat different but valid approach. Further research could investigate the relationship between structural power and biographical disruption, thus enhancing and extending the scope of this study.

In other words, this research suggests how intersectional identities of two social actors shape a dynamic that allows belonging or strangeness to be negotiated. Again, the focus of the study is how participants make meaning and modify their interpretations and behaviours to renegotiate belong and strangeness after a life changing event.
Additionally, the intersectional approach in this research considers power dynamics in relation to health disruptions, such as societal stigmatization. However, its primary goal is to delve into how intersectionality influences the process of negotiating belonging and dealing with strangeness. For this purpose, the research concentrates on examining the intersectional aspects of individuals' identities and the values they choose to embrace, reject, perform, or conceal during social interactions. This exploration aims to shed light on how these choices affect the intermediate stages of interactions, shaping the revaluation of belonging and strangeness.

The research focuses on the human response to uncontrollable (and sometimes unexpected) changes in lives. Disruptive events involve dealing with modifications in constructions of aspects of self-identity and can involve a process of loss, such as the one suggested by shattered assumption theory (Janoff-Bulman, 1989) and discussed further in Chapter 2. The process of self-identity construction after a health disruption involves renegotiation of belonging and strangeness that can be painful but can also lead to self-development and new bonds of belonging, as well as new layers of belonging in existing relationships.

In this sense, this thesis views individuals as active social actors who have agency and can utilise it in creative ways. Specifically, Chapter 7 focuses on intersectional processes of self-identity construction and strategies that individuals choose during life transition. In other words, people have agency when constructing their self-identities. Even when society imposed roles or strangeness on the participants, they were able to construct interpretations and perform behaviours in order to execute their choice about self-identity construction. By examining the ways participants negotiated their sense of control and safety and how they operated intersectional processes, the research offers a model for understanding individuals’ self-identity construction after a life-changing event.

**Summary of Chapters**

Now that I have provided an overview of the study context and research questions, I present how the following chapters provide the basis to understand belonging and strangeness negotiation after a life changing event.

**Chapter 2** discusses Bury’s term of “biographical disruption” to examine how major life transitions disrupt everyday life, further plans and aspirations. Biographical disruption undermines taken-for-granted assumptions and behaviours, along with explanatory systems that are examined through the theoretical framework of shattered assumptions (Janoff-Bulman, 1989). This framework unpacks the
importance and complex role of basic assumptions individuals have about the world and about their own value. In addition, it addresses the process that is triggered by the undermining of those assumptions, and the impact it has on self-identity. As such, biographical disruption that involves shattered assumptions impacts individuals’ sense of control and trust, and thereby belonging and strangeness negotiation. However, biographical disruption can also lead social actors to utilise their agency for the purpose of biographical work and develop new skills, knowledge and circles of belonging to cope with a transition. In this regard the social and affirmative models of disability are reviewed and analysed according to the potential to negotiate belonging and strangeness after a disruptive event.

Chapter 3 reviews the concepts of belonging and strangeness. As inherently related concepts, the two function as key elements in constructing self-identity and are particularly important during life transitions as they motivate social actors’ formation of self-identity. The existence of “the other” in social actors’ lives will also be addressed as it directly impacts self-identity construction. As stated above, belonging and strangeness are perceived as symmetrical concepts that are inherent in each other, as the conditions for their negotiations are similar, as well as some of the needs social actors have during self-identity construction. As mentioned before, belonging and strangeness negotiation, as well as self-identity construction, cannot be understood without grasping the intersectional process. That is because intersectionality is associated at any given point with interactions that involve belonging or strangeness negotiation, and this process motivates the performance of a particular intersectional identity. To illustrate this complicated dynamic, I briefly present two participants narratives from the main study to give life to these theoretical ideas.

Chapter 4 presents the pilot study that was conducted in New Zealand to develop the sensitising questions around biographical disruption for the main study in Israel. In addition, the chapter reviews theoretical decisions that were made. The chapter also outlines how I used an intersectional approach with narrative methodologies. As mentioned before, the research is based on micro-level constructionist methodology that assumes social actors are active agents that operate within social structures, and construct their interpretations and self-identity. These commitments informed my methods of conducting multiple interviews with eight Israeli participants about their experiences of acquiring a major physical disability. Central to this chapter is the discussion of how I analysed this data and the associated ethical implications of engaging with people multiple times to talk about their experiences of responding to, and making meaning of, such disruptions in their own lives.
Chapter 5 focuses on the importance of a sense of control and explores how it impacts individuals’ agency after a biographical disruption. More specifically, it focuses upon different types of control that are available in uncontrollable times and explores how these overlap with the multiple contexts of the participants’ lives. As the participants were encumbered with a stigma for their bodily condition, they sometimes had to cope with a loss of control that is related to belonging negotiation. However, although stigma is characterised as a social trait that is out of an individual’s control, it can be managed through construction of interpretation and narratives that deflect it and empower labelled individuals, as the participants have demonstrated. To conclude, this chapter focuses on individuals’ need for a sense of control during belonging and strangeness negotiation, which affects self-identity construction process after a life-changing event that was neither chosen by them, nor is fully controllable.

Chapter 6 begins with a discussion of home that represents a spatial and conceptual aspect of safety. The rest of the chapter revolves around trust as the social aspect of safety that is relevant for belonging negotiation. Trust is strongly linked to control, as trust requires risk taking and may undermine a sense of control. However, trust and control hold more complicated and sometimes complementary relationships. This discussion is also related to the claim that trust is a form of agency that requires the development of social intelligence that directs who should and should not be trusted, hence impacts belonging and strangeness negotiation. In particular, I illustrate how the participants’ experiences portray construction of trust, control, or both. Their narratives reflect the challenges they coped with during biographical disruption and how a development of the meaning of safety becomes modified after a biographical disruption.

Chapter 7 unpacks the question of choices, and especially those made regarding self-identity construction. It firstly asks what the motivation would be to choose negotiation of belonging and what should motivate strangeness construction. The participants’ drastic life changes were not experienced by choice, and this impacts not only motivational factors, but also agency utilisation for self-identity construction. The chapter examines the different choices participants make in shaping their agency during belonging and strangeness negotiation after a disruptive event. It focuses on choice on two levels: the first level relates to notions of safety and control, while the second level relates to choices of intersectional identities that are related to disability during negotiation of belonging and strangeness. In other words, the meanings that are embedded in the participants’ intersectional identities impact the course of an interaction and the potential for belonging or strangeness negotiation.
Chapter 8 synthesises the concepts presented in the previous three chapters by introducing the CSC model, which revolves around the challenges and needs of people who experience biographical disruption. As mentioned before, notions of control, safety and choice circle around the process of identity construction and belonging/strangeness negotiation after a drastic life change. The model suggests a direct linkage between an action of choice that is related to safety, control, and intersectional identity as part of identity construction after a life-changing event.

Conclusion
This thesis seeks to expand the contexts of acculturation to other contexts that do not necessarily involve a geographical relocation. Data from this study suggests that the idea of adaptation within contexts of uncertainty is an important commonality between the experiences of people with acquired physical disability and immigrants. Thereby, although disability has been chosen as the case study for this research, this study opens the possibility that there are numerous examples of life-changing events that could fruitfully engage with acculturation theories.

Questions about self-identity construction are relevant to the idea of transition and meaningful change, and are explored in this research through the lenses of a drastic life change, as such change reveals the condition that are required for belonging and strangeness negotiation. For this purpose, this research explores a variety of concepts and utilizes theoretical ideas of scholars from multiple research fields. This is because the ideas that this research explores are complex, and unfolding was a challenging task in itself. However, the usage of different theoretical ideas from different fields all have a common goal, which is to reveal the constructionist understanding of reality that human beings develop. As mentioned before, this dissertation views individuals as active agents with a freedom of choice about their interpretations and behaviours. Thereby it utilizes different scholars to portray a social world of interpretations that motivates behaviours.

This study is pioneering and offers a new theoretical framework of understanding acculturation theories. Thus, it does not present a perfect and complete picture of self-identity construction processes, but rather seeks to raise additional questions that can help understand acculturation processes in relation to life-changing events other than migration. Further research, for example, could examine acculturation processes that are experienced by people who choose to change their lives in a significant way, as opposed to the participants in this research who did not choose to experience a life-
changing event. In other words, this work should be evaluated not only by the ideas it presents but also by its potential to stimulate the reader’s interpretation process regarding the questions it raises.

Chapter 2: Biographical Disruption

Introduction
This chapter discusses the origins of the concept and its impact on belonging and strangeness construction, and the effects this process can potentially have on self-identity. Biographical disruption that results from an acquired physical disability intertwines a notion of bodily function with that of identity, and suggests the two are linked. People manage their identities, construct meanings, and establish performance during social interactions in an aspiration to reconcile the different aspects of their identity that were affected by a “disruptive event” (Bury, 1982). Identity development during biographical disruption that results from chronic illness or an acquired physical disability can shape the way individuals see themselves, their bodies, and their way of interacting with the world (Forber-Pratt et al., 2017).

As mentioned in the previous chapter, health disruptive events can involve different types of bodily crisis. For example, physical disabilities can result out of chronic illness, and thereby a distinction between them is difficult to be made. Both individuals who experience a significant acquired physical disability would encounter challenges if trying to reconstruct their self-identity as before, as a bodily change directly impacts this process. Such disruptive event would involve a “language of loss” (Charmaz, 1983) that reflects the different aspects of self-identity that cannot be performed due to a life changing event. In addition, health disruption does not change only the life if an individual who acquires a physical disability or has to cope with a chronic illness, but also their family, and other members of their intimate social networks. Furthermore, in both cases individuals are sometimes expedited to ‘be repaired’ before there are allowed to fully participate in civil society. Lastly, both individuals with chronic illness and/or an acquired physical disability may become stigmatised by others and manage a coerced strangeness. That is, due to an uncontrollable physical condition that is visible or not, all the
participants in this research had to cope with a potential of a stigma that impacts renegotiation of belonging and strangeness.

Having said that, there are fundamental differences between the experience of acquiring a physical disability and chronic illness: firstly, chronic illness would lead to hospitalizations rather than rehabilitation as in the case of an acquired physical disability. Secondly, there is an element of uncertainty that involves chronic illness: prolonged or incorrect diagnosis, an uncertainty about its progress, etc. would shape the experience of individuals with chronic illness differently than those with acquired physical disabilities. In this regard it should be reemphasized that this research focuses on renegotiation of belonging and strangeness after a life changing event, which means it could have included numerous examples of disruptive events, however by keeping the research scope within the medical field it easier to make the theoretical claims about self-identity construction after a life changing event.

As mentioned in the previous chapter, the agency that social actors utilize after a life changing event to renegotiate belonging and strangeness is at the centre of this research. For this reason using the term "health disruptions," I am able to encapsulate the various events and circumstances within the medical field that can profoundly impact self-identity construction after a life-changing event. This concept aligns with the research's central focus on how individuals navigate the complexities of belonging and strangeness in the aftermath of such events. It allows the research to encompass a range of medical scenarios that may lead to shifts in self-identity and agency, making it a suitable and encompassing concept for this thesis.

Biographical disruption involves questions of social categorization and meaning making, along with physical and biological aspects (Forber-Pratt, 2017). Biographical disruption that results from body crisis involves, according to Bury (1982), the

...recognition of the worlds of pain and suffering ... which are normally seen as distant possibilities or the plight of others. As such, biographical disruption brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. (p. 169)

In other words, becoming dependent on others, the loss of social networks and growing isolation (Locock et al., 2009) could be the result of a process of biographical disruption. In other words,
becoming dependent on others, the loss of social networks and growing isolation (Locock et al., 2009) could be the result of a process of biographical disruption. Janoff-Bulman’s (1987) theory of shattered assumptions, for example, is examined in order to understand the loss of a sense of control, and the associated grief that is experienced by individuals whose basic schemas about the world are shattered and no longer valid. As such, shattered assumptions can become part of the experience of people who experience health disruptions. While acknowledging the significance of shattered assumptions, this research focus shifts toward examining individuals' agency, interpretations, behaviours, narratives, and other aspects that come into play when they confront this loss of control. By concentrating on these aspects, the research is delving into the coping mechanisms and strategies that individuals employ to navigate through the uncertainty and unfamiliarity brought about by a life-altering event. This focus aligns with the objective of understanding how people manage the renegotiation of their sense of belonging and strangeness in the aftermath of such an event. In this regard, I focus mainly on Bury’s and Janoff-Bulman’s (1982, 1989) writing as they provide a solid theoretical base for the development of questions about self-identity development in regards to biographical disruption. Their theoretical ideas are relevant to explain the principal dynamic of identity shift and belonging and strangeness negotiation after a disruptive event.

Biographical disruption is usually the result of an unexpected life-changing experience that undermines pre-existing mental schemas—most particularly those that are related to assumptive worlds. This has a direct impact on a sense of loss and uncontrollability that can undermine one’s belonging construction and can lead to identity crisis. This chapter explores how biographical disruption that is caused by a health disruptive event interrupts one’s self-identity construction, and may lead to notions of estrangement from society and self. A coerced attachment to a stigmatised group, as in the case of the participants in this research, corresponds with other experiences of individuals who become part of a discriminated-against group during their lives, as in the case of ethnic minority groups (Jayara, 2020). This suggests that social structures are set around boundaries of belonging and strangeness, in other contexts as well. This idea corresponds with the perspective of the social model of disability, which will be discussed later in this chapter. The social model of disability claims that physical disability is not the reason for discrimination, rather than society’s construction of the meaning it has on one’s self-identity. Thereby it challenges a belonging and strangeness negotiation process of people with disabilities to “able-body” society.
This chapter reviews how a loss that involves biographical disruption can be processed through biographical work that aims to construct self-identity with values that are not necessarily related to bodily function. Biographical work can also relate to the affirmative model of disability that provide opportunities for belonging construction, which can lead to self-acceptance, empowerment and celebration of human differences, as will be discussed later in this chapter.

**Historical Perspectives**

The research on which Bury based the concept of biographical disruption took place between 1976 and 1979 in Manchester, UK, with a group of 30 patients who were first-time referrals to a rheumatology clinic (Locock & Ziebland, 2015). Bury (1982) was most interested in the way chronic illness disrupts everyday life, future plans and aspirations, and his conclusion led to a “fundamental rethinking of the person’s biography and self-concept” (p.169). As a result of chronic illness, the body becomes an “unknown terrain that must be relearned” (Becker, 1994, p. 385) and as such becomes the focus of self-identity. As an unstable being, the body is differentiated from previous self and becomes an erratic ground on which a new order, routines, and assumptions must be constructed (Becker, 1994).

There are three aspects of disruption that may take place during chronic illness, according to Bury (1982):

- **Taken-for-granted assumptions about the self, and about how the world is, may be undermined by a disruptive event as one’s subjective experience demonstrates that bad things happen to good people, and perhaps there is no real justice in the world.**
- **Explanatory systems that are fundamental for one’s perception of self can be disrupted and would impact individuals' agency as a result of chronic illness.**
- **A reaction to a disruptive event would usually involve mobilisation of resources.**

More recent studies have added further insights to the term: for example, Green et al. (2007) claim that biographical disruption that evolves out of chronic illness may jeopardise not only patients, but also members of their household, as there is a high likelihood that they “will need to rearrange their collective lifestyles to accommodate Illness” (p. 526). Similarly, individuals who cope with and manage an acquired physical disability do so as they engage in self-identity development that involves strangeness and impacts their families and immediate social circles (Forber-Pratt et al., 2017). Moreover, although biographical disruption occurs as a reaction to an initial chronic illness diagnosis, there are also recurring disruptions (Locock & Ziebland, 2015) that, like earthquake aftershocks, “take
place with the repeated transitions due to bodily and functional losses over the life span” (Larsson & Grassman, 2012, p. 1157).

Biographical disruption can lead to an undermining of existing schemas that are the base for self-identity construction, as will be explained later in this chapter. This could jeopardise not only self-identity construction but also belonging and strangeness negotiation. Loss of aspects of identity, of a previously foreseen future and of truths that were part of individuals’ schemas, could lead to a sense of loss that involves grief. Despite that, people with an acquired physical disability are not always given the permission to grieve over this loss and their grief might become “disenfranchised” (Doka, 1989). This type of grief, according to Doka (2008), is produced when a person experiences a significant loss and the resultant grief is not openly acknowledged, socially validated, or publicly mourned. There is no greeting card for the acquisition of a disability (Smart, 2012), and thereby people with an acquired disability can be denied the process of grieving which, according to Thompson (2002), can allow people to reconstruct meaning to their lives. A denial of their grief adds to the possible identity crisis that results from biographical disruption, thus producing the potential to construct strangeness towards others. However, the development of this process will not necessarily take place as individuals are active social actors who utilise their agency to construct interpretations about themselves and their lives, and thus are capable to draw conclusions that can, for example, reaffirm their existing networks of belonging in a way that contributes to their well-being and reduces the negative impacts of biographical disruption.

Bury (1982) drew upon Giddens’ concept (1979) of the “critical situation” which was related to war implications such as displacement, in order to understand how an unexpected diagnosis challenges former expectations, and the adaptation it requires (Locock & Ziebland, 2015). Critical moments, or fateful moments (Giddens 1991), are “times when events come together in such a way that an individual stands at a crossroads in their existence or where a person learns of information with fateful consequences” (Giddens, 1991, p. 113). During these times, the routines of everyday life are disrupted, and people face crucial choices for which they assert risk assessment (Mulhall, 2013). During critical moments, or biographical disruption, social actors are viewed as active agents; Giddens (1991) suggests that in such times individuals are engaged in identity work, utilise expert systems, seek advice and develop new skills. Bury (1982) developed this standpoint to biographical work, which is the process that social actors purposefully manage and adapt during drastic changes (Larsson & Grassman, 2012). For example, management of a physical condition that disrupts everyday life is of high importance (Bury,
1991), searching for relevant information, seeking professional advice (Bury, 1991), and mobilisation of resources (Bury, 1982) are practices that would assist not only with physical symptoms management but also with negotiating one’s belonging and strangeness, as will be elaborated later in this chapter.

As discussed before, these theoretical ideas suggest that the principal process of biographical disruption can be extended and applied to other health disruptions: in both events of chronic illness and an acquired physical disability, a sudden and unexpected event leads to an interruption in identity construction that impacts individuals and their intimate social networks. Both carry the risk of experiencing a biographical disruption that would affect numerous aspects of individuals' life and would be accompanied by later reoccurring disruptions. In addition, both are at a risk of being stigmatised by others, based on their physical condition. This leads to an intersectional process in which one’s physical condition is the only aspect in which their identity is evaluated upon, as will be elaborated in Chapter 7. However, the political discourse to such a stigma is utterly different between communities of people with disabilities and with chronic illness. For this reason this research would focus on models of disability as a political stand view to understand a community’s effort to challenge stigmatisation and coercion of otherness. Having said that, the two experiences still share many features, as mentioned before, and are useful for this research as they both demonstrate a biographical disruption that is related to a physical condition.

However, as mentioned earlier in this chapter, a main difference between the two groups is that chronically ill individuals may be hospitalised during their experience of biographical disruption, while people with acquired physical disability usually go through rehabilitation that aims to incorporate bodily changes in order to develop different levels of individual independence. This research will use the term biographical disruption in relation to individuals who acquired a significant physical disability, but were able to maintain their identity work outside of medical institutions and reflect upon the difference in self-identity that operates in its “natural habitat.” Both groups would have had to address a significant change in life that involved coping with the undermining of existing schemas and biographical work. These processes impact one’s worldview and view of self-identity, as one navigate through a disruptive event and its implications, and thereby are lucrative for this research.

Despite these differences, utilizing the term “health disruption” in this thesis is useful because it encompasses a wide range of health-related factors and contexts. It emphasizes the significant impact on different aspects of health, making this research broader and more compelling. This term encourages
a multidimensional perspective, recognizing the complex interplay of factors affecting health. By reframing different physical conditions as health disruption, this research may focus on the experience of renegotiating belonging and strangeness after a life changing event, rather than focusing on the particular medical context that revolves around it.

**Shattered Assumptions**

Biographical disruption, according to Bury (1982), disrupts taken-for-granted assumptions and behaviours (Exley & Letherby, 2001), along with people’s explanatory systems that are the basis of mental schemas (Exley & Letherby, 2001). In fact, those who experience biographical disruption have to address a “reordering” of their biography and self-identity (Exley & Letherby, 2001). This mission becomes even more complicated if a disruptive event such as chronic illness leads to uncertainty—both in knowledge about the impact and course of treatment (Bury, 1982) and of “the appropriate behaviour in the face of its effects” (Bury, 1982, p. 172).

In Bury’s (1982) view, a “disruption of taken-for-granted assumptions and behaviours” (p. 169) means that people who experience biographical disruption cope with loss of sense of control as previous schemas lose their relevance after a life-changing event. Schemas are used by individuals to construct their perception of reality; they function as preexisting theories that guide individuals in not only how to grasp reality but also in how to interpret it (Janoff-Bulman, 1992). People’s assumptions are learnt and confirmed (Parkes, 1971) and are utilised to produce schemas which are the abstract knowledge structure that form presumptions and expectations that people have about concrete and hypothetical situations and are in use when new information is presented (Janoff-Bulman, 1989).

The schema concept extends from grasping common object categories to social categories that include individuals’ judgements and perceptions of others and themselves (Janoff-Bulman, 1989). In addition, people hold schemas for social events, which are often referred to as “scripts,” which are mental structures of event sequences in familiar situations (Janoff-Bulman, 1989). Individuals strive for coherence in their schemas and will attempt to incorporate and understand changes that drastic life events bring upon them (Janoff-Bulman, 1989). At the same time, however, people can demonstrate conservativeness when it comes to changing schemas and will strive to hold on to previous schemas rather than develop new ones (Janoff-Bulman, 1989). In other words, individuals regularly seek and recall information that is consistent with original self-schemas (Janoff-Bulman, 1989).
A drastic life change that involves biographical disruption, however, puts people’s original schemas in danger as a life-changing event that is too vivid and overwhelming cannot be ignored. As such, a health disruption directly impacts the validity of people’s schemas. In such events, previous schemas cannot be utilised as before to construct the meaning of events. As a result, these schemas may be rejected while others will be adopted; however, due to the nature of a health disruption people may develop more negative assumptions about the world and sometimes of the self (Lilly et al., 2011).

Janoff-Bulman (1989) suggests particular schemas which are related to the nature of the world and self that are specifically vulnerable after a disruptive event: *assumptive world*, a term offered by several scholars (for example Bowlby, 1969; Marris, 1975; Parkes, 1971) is used by Janoff-Bulman (1989) to claim that people hold assumptions that allow them to successfully navigate through their external environment, promoting optimal encounters and enhancing their chances for positive outcomes (Lilly et al., 2011). Assumptive world’s theory explains how people’s agency is influenced by three basic views that comprise their perceptions: the world is benevolent, the world is meaningful, and the self is worthy (Lilly et al., 2011).

The world as benevolent refers to the assumption that we live in a safe environment and that people are good, caring, kind and helpful (Lilly et al., 2011). This level of schema supports an underestimation of individuals’ vulnerability to misfortune, and is constructed in order to protect against potential stress and anxiety that may be associated with such threats (Rodriguez-Munoz et al., 2010). The world as meaningful implies a perception of the world as comprehensible, controllable, predictable, and just (Rodriguez-Munoz et al., 2010) and, as a result, leads to the notion that it is possible to control what might happen in the future (Lilly et al., 2011).

As part of the world’s trait as just and right, it is expected that misfortune would occur to immoral and corrupt people, while good and just things would happen to decent and moral people. Justice, then, can be translated as a form of control, a belief that people’s agency leads to desired outcomes (Rodriguez-Munoz et al., 2010). Hence an undermining of this level would inevitably lead to self-identity crisis (Rodriguez-Munoz et al., 2010). Perceiving one’s self-identity as worthy, decent, capable and moral means that a disruptive event may shatter such perceptions of the self and would challenge self-identity construction and social relationships (Lilly et al., 2011). It may even lead one to withdraw from activities that are commensurate with one’s abilities and previous self-evaluation (Lilly et al., 2011).
Biographical disruption that results from an unexpected health disruption can involve different processes, such as shattered assumptions. The realisation that the world is not just and is uncontrollable directly impacts one’s perceptions of self-identity and others, and affects belonging and strangeness negotiation, as will be explained in the next chapter. This research employs Janoff-Bulman’s theories to comprehend the encounter with health disruptions. While trauma and loss constitute essential elements within the shattered assumptions theory, this research takes a different trajectory. It does not centre on trauma or cultural trauma; rather, its focal point is on the interpretations and cultural constructions that come into play during the process of redefining notions of belonging and strangeness following a health disruption. The phenomenon of existing schemas losing their validity necessitates a process of identity work, involving the construction of new schemas. Within this context, social actors feel an inherent need to reestablish both control and trust.

A Sense of Control

As mentioned earlier, biographical disruption can involve a process of shattered assumptions and undermine the sense of control; individuals would have to cope with its loss, and activate their agency to regain a renewed sense of control. When a life-changing event takes place, people can utilize their agency to reconstruct primary control in which an active behaviour can lead to the solution of problems. In the case of health disruption individuals would not be able to use primary control to turn the wheel back and delete a disruptive event from their biographies, but it does not mean they could not utilise their agency. There is no doubt that health disruptions put them in a complicated journey—one that is often unexpected and undesired. It is a journey that places them in a position of increased marginality that signifies the precarity of primary control but also indicates that people can still find ways to shape their future.

Instead of primary control that is associated with a performative action that aims to impact the external world, individuals can construct secondary control that is centred within one’s cognitive process (Rothbaum et al., 1982) and assists with coping with events that are uncontrollable. This issue will be further discussed in Chapter 5; however, at this point it is important to emphasise the characteristics of secondary control, as it takes place first and foremost within the individual’s mental structure.

Secondary control is a type of control that does not need to be exercised in order to be effective, as the mere perception of control can be enough to have positive effects on people (Rothbaum et al., 1982). However, it is sometimes referred to as perceived control (Rothbaum et al., 1982). According to
Rothbaum et al. (1982), perceived control is an idea that is rooted in the understanding that a sense of control is mostly an illusion that was invented to cope with the uncontrollability of the world. In other words, perceived control indicates that control has not existed prior to biographical disruption and will not be grasped after it; hence, processing this understanding leads to a smaller decrease in one’s sense of control. Perceived control is the belief people have that they can exercise control over a situation, either by controlling their outside environment or themselves (Rothbaum et al., 1982). In fact, people’s belief that they can exercise control over a situation, either by controlling their outside environment or themselves, is really *perceived* control over that which is actually uncontrollable. Having said that, even when a sense of control is perceived at a given moment, an actual sense of control can be gained. For example, such sense of control can reduce the tension that is involved in the need to keep searching the environment for imminent stimulus (Rothbaum et al., 1982) during a biographical disruption. In fact, perceived control can predict positive outcomes including resilience, motivation, cognitive functioning and life satisfaction (Rothbaum et al., 1982) and can even affect the physiological system by reducing high stress and pain (Greenaway et al., 2015).

In addition, as secondary control is intended for the purpose of the person that constructs it, the definition of control as perceived is problematic as this sense of control is intended to be effective only in the mind of those who construct it. It is true that it can be defined as “perceived” by others; however, this view is missing the purpose of secondary control overall, which is providing a sense of control for individuals who construct it for themselves. Therefore, it should be acknowledged that the term perceived control is utilised only by others, who are external to the individual who constructs secondary control as part of their agency. However, the concept of perceived control emphasises the misconception we all have regarding the controllability we imagine that we have in our lives. Lefcourt (1973), for example, argues that “the sense of control, the illusion that one can exercise personal choice, has a definite and positive role in sustaining life” (p. 424). That is, although perceived control depends on one’s abilities to manipulate ways to achieve one’s goal, it does not have to have a basis in reality.

In fact, in many cases control exists only as the final goal of a mental process, as most of life’s aspects cannot be controlled. As such, secondary and perceived control do not necessarily have a direct link between external reality and inner sense of control. For example, when one aspect of life is uncontrollable, people may seek to develop a sense of control in other areas of their life. For example, one may utilise rituals to reconstruct a sense of control at times of misfortune.
Langer (1975) proposes that people fail to distinguish between objectively controllable and uncontrollable events; she hypothesises that factors associated with people’s skills, such as practice, competition, choice etc., lead people to perceive a degree of control over outcomes when introduced to chance situations (Presson & Benassi, 1996). In other words, overestimating one’s ability to control situations is a biased construct that helps to shape people’s schemas, while in fact they may have not impacted or had any control over an event.

Of course, during biographical disruption that stems from a health disruption there are objectively measured factors that can indicate physical improvement and promote reconstruction of identity aspects as before. This can impact positively on a sense of control that an individual would construct and as a result could have a similar effect on their well-being. However, the main point made here is that secondary control can lead to a sense of perceived control, regardless of physical symptoms. Indeed, people can cope with a biographical disruption in a variety of ways: one person’s sense of control may be unharmed, while another may experience a great deal of loss of control. What could be the source of this difference?

One of the ways to address this question is related to the second important factor during belonging negotiation: trust. Trust is the social dimension of safety, along with “home” that stands for its spatial dimension. Belonging can lead to a sense of safety, but trust is a necessary component for this process. Therefore, the interweaving of trust and control impacts directly on belonging and strangeness negotiation, as will be explained in Chapter 6.

A Sense of Trust
Shattered assumptions theory is relevant to this research not only in terms of understanding the concept of control but also the notion of trust, as the theory differentiates between events that were “human-induced” and noninterpersonal events, and their impact. Human-induced trauma events will have a more detrimental effect on the core conceptual system. This happens because they include principal differences in an intention to hurt and the victim’s role in the event (Janoff-Bulman, 1992).

Interpersonal trauma may involve good intentions that fail to acknowledge their own biases presumptions, or even worse—the evil intention of a perpetrator whose actions can cause the victim to question personal autonomy and strength of will. This could shatter individuals’ self-worth and belief in a meaningful, benevolent world, and that would undermine assumptions of other people’s trustworthiness (Lilly et al., 2011). This could also decrease motivation to construct trust with others,
hence reduce potential for belonging construction. A sense of trust that is constructed towards others may be influenced by the negative impacts of previous interpersonal trauma and lead to a construction of strangeness. For example, interpersonal trauma could lead to a perception of the social environment as unsafe and dangerous and lead to self-blame, loss of autonomy and experiencing the self as incompetent, weak, and powerless (Lilly et al., 2011).

The dichotomy Janoff-Bulman (1989) offers between interpersonal and noninterpersonal trauma suggests that individuals’ (who experience health disruptions) schemas about the world as good and safe would not be directly undermined, hence construction of trust with others will not necessarily be undermined. Having said that, later in this thesis (Chapter 6) biographical disruption will be unpacked to understand how a sense of trust can be undermined and decrease the potential for construction of a sense of belonging. Medical professionals, for example, who are trusted initially as a result of their social role (Sztompka, 2000) may breach that trust and undermine an initial perception that all doctors can be trusted. In other words, although noninterpersonal disruptive events do not impact directly on people’s world of assumptions, later events of loss of control and trust may contribute to a similar degree as interpersonal trauma does. As people discover that they are unable to control the course of events, both interpersonal and noninterpersonal traumas can lead to a sense of powerlessness and hopelessness as which can lead to self-questioning (Lilly et al., 2011). Health disruption may lead, in other social contexts as well, to individuals’ feeling of being objectified and labelled with a stigma due to their physical condition. Such processes may lead to development of discriminating events and a sense of imposed strangeness that challenges even more their belonging negotiation.

**Discriminatory Events.** Experiencing discrimination may confront individuals with a process of shattered assumptions, as claimed by Foster et al. (2006) who suggest that the scope of negative influences that discrimination based on group membership has on individuals is wide, and can lead to negative mental health symptoms such as decreased self-esteem, increased depression and anxiety, as well as negative physical symptoms. If people assume the benevolence of the world, then experiencing discrimination after a disruptive event would undermine that schema, and as a result shatter the assumption of personal invulnerability (Foster et al., 2006). In principle, a personal crisis takes place when there is no longer a match between an individual’s beliefs (how they think the world operates) and their actual experiences with the world (Foster et al., 2006). In such case a health disruption would impact in a way that redesigns basic schemas (Foster et al., 2006). Psychological well-being can increase, however, when
schemata become more consistent with those experiences (Janoff-Bulman, 1992). This means that in order to promote their well-being, individuals strive to reconcile their previous perceptions and schemata with their experiences during and after a biographical disruption, and do so by constructing interpretations that are able to accommodate the two. At this juncture, it’s important to reiterate that Janoff-Bulman’s theories significantly aid in comprehending the intricacies of health disruptions. However, it is crucial to note that the focus of this research will diverge from an exclusive examination of trauma experiences. Rather, the research focuses on how individuals navigate the challenging experience of constructing a sense of control and trust in the face of health disruptions that undermines them. Experiences of discrimination clearly do not always lead to significant disruptive events or a trauma. In fact, Janoff-Bulman and Frieze (1983) have explicitly distinguished trauma victims from victims of discrimination and claim that their psychological challenges may be very different. Assumptive world theory, according to Janoff-Bulman (1989) refers mainly to victims of extreme or out-of-the-ordinary events rather than those who experience an ongoing discrimination (Foster et al., 2006). Yet the theory can provide important insights about the psychological reactions of victims of discrimination as well (Foster et al., 2006).

As mentioned before, psychological well-being is increased when schemata become more consistent with people’s experience (Janoff-Bulman, 1992). This means that if a person experiences discrimination daily, for example, believing that the world is good and just may create a dissonance with their experiences, and lead to realisation of their misinterpretations and to a possible identity crisis (Foster et al., 2006). A health disruption can lead, therefore, to a conflict between the ways people experience the world as benevolent and just until a particular point, and the way the world interacts with and discriminates against them after that point. These contradictions can lead to a crisis because shattered assumptions and coping with stigmas impact people’s ability to construct their belonging as before, and compel them into a position of strangeness. This results in a disruption in self-identity construction that needs to be addressed.

Firstly, health disruption can lead to an acquired understanding about a stigma attached to one’s identity, and to a later realisation that the belief that an individual’s success is a factor of an individual’s ability or effort is in fact, wrong, and the world is not meaningful and just (Foster et al., 2006). Secondly, the assumptions of personal invulnerability can become relevant due to experiences of discrimination in case of physical, socio-economical or psychological harm (Foster et al., 2006). In fact, interpersonal
events of discrimination can undermine basic schema about the world’s benevolence and meaningfulness; however, that is a more complex process that does not happen at once like health disruption usually do (Foster et al., 2006). In such case, events of discrimination accumulate, and, as a result, individuals realise that the world does not follow their original perceptions (Foster et al., 2006). Indeed, health disruption that includes managing stigma leads to further secondary disruptions that involve discrimination and challenge the ability to negotiate belonging as before a disruptive event; a process of stigmatisation can lead to loss of trust in others, and a disruption in self-identity construction may impact trust reconstructions with others in their intimate social networks.

Loss of trust in medical institutions and professionals, or loss of trust in relationships, which people who experience health disruptions experience when a process of stigmatisation takes place, can undermine belonging negotiation processes. Health disruption leads to an undermining of existing schemas about the world and self, which further undermines two main domains: control and trust, which in turn react and impact on belonging and strangeness negotiation processes. The different factors of belonging, strangeness, control, safety (trust and “feeling at home”) impact one’s self-identity construction directly. As will be elaborated in the next chapters, individuals have the ability to activate their agency when facing unfamiliar and unexpected situations. However, the implications of health disruption should be first unpacked, as undermining of one’s sense of control and safety would lead inevitably to a sense of loss.

A Sense of Loss
According to Bury (1982), during biographical disruption there is a growing attention to physical and mental pain that can lead to a sense of “bodily alienation” or “betrayal.” However, the pain is not limited to the physical aspect, as mentioned before. Along with the potential to reach “epiphanies” or moments that are privileged in their possibility for changing one’s life (Locock et al., 2009), there is an undeniable aspect of loss. Charmaz (1983) refers to a “language of loss” that is associated with chronic illness, as such an experience involves events in which a crumbling away of original self-images takes place and, moreover, without simultaneous development of equally valued new ones. For individuals with an acquired disability the situation is different as rehabilitation should motivate them to reconstruct a self-identity that includes a physical disability, however the principle of a lost self-identity, an identity that cannot be constructed as before – remains in both types of health disruptions. During health disruption, schemas that reflect the way people have known themselves in the past become
increasingly remote as a drastic life-changing event sets a boundary between an individual’s past and present self (Charmaz, 1983). Furthermore, if an individual’s independence is jeopardised due to their physical condition then a sense of “becoming a burden” will emerge, followed by a “loss of hope and loss of recapturing positive self-images of the past” (p. 188).

An individual who can no longer claim and perform previous aspects of self-identity and is in an inferior position to negotiate them (Charmaz, 1983) may feel they are becoming a burden. In such cases, an individual can experience not only a feeling of uselessness to self and loss of self-value, but also a feeling of loss of control, which are all linked to loss of the self (Charmaz, 1983). It is not only control related to the body or schematic relevance that is associated with such loss, but also loss of spectrum of choice and freedom that were part of life before becoming restricted by a physical condition (Charmaz, 1983). These feelings naturally impact the way individuals view themselves, as well as the way they view others, and thereby their belonging negotiation will be impacted directly by a sense of loss.

**Biographical Work**

A significant part of understanding biographical disruption is biographical work—a process that involves construction of meaning out of individuals’ experiences (Bury, 1982). This course of development is not only a part of reconciliation between the difference in one’s identity before and after a disruptive event, but also stands as a means for coping with a social stigma that may be attached (Goffman, 1963) as a result of a health disruption.

Both Bury (1982) and Charmaz (1987) address the issue of “repair” and explore the mechanism of biographical work that people are able to apply as part of their agency and in relation to belonging (Locock et al. 2009). Charmaz (1987), for example, claims that people have the agency to conduct an *identity hierarchy* from which they can select a relevant identity in different contexts (Carriacaburu & Pierret, 1995). She claims that “the types of preferred identities constitute particular identity levels in the identity hierarchy. Among these different levels of] the restored self is a reconstruction of previous identities before illness” (Charmaz, 1987, p. 285). The hierarchy Charmaz (1987) identifies suggests individuals’ ability to pursue particular preferred identities depends, among other factors, on the type and degree of illness and its timing and sequencing. Some people may try to “continue as normal” and attempt to resume their former lives and sense of themselves (Charmaz, 1987) and avoid threats over existing bonds of belonging. In other cases, people may achieve “identity repair” by accepting and adapting the changes in their lives (Charmaz, 1987) and as such allow bonds of belonging to modify as
well. In some cases, strangeness will be developed in regard to other people, relationships or social roles; however, life may also provide opportunities to develop new bonds of belonging or adapt the varieties of identities that disruptive events catalyse.

Mobilisation of resources involves utilisation of cognitive mechanisms for learning how to tolerate or put up with the effects of a disruptive event (Locock & Ziebland, 2015). In fact, individuals can utilise different capital forms, such as physical, social, financial, medical and cultural, to gain a new order in their life after a disruptive event (S. J. Williams, 2000). Resources mobilisation is a crucial part in an individual’s coping with and managing biographical disruption. It is aimed to minimise the implications of bodily dysfunction for one’s self and collective identities, in order to construct self-identity as before and maintain an as intact sense of belonging as possible (S. J. Williams, 2000). These processes include an element of repair of a sense of coherence (S. J. Williams, 2000) that allow an individual to establish a sense of control. This could lead to an establishment of a sense of potency that will contribute to a reconstruction of “a new normal life” (S. J. Williams, 2000).

Thus, individuals are potentially able to reconcile their past, present and future. Part of resources mobilisation could be categorised as “strategies” that refer to actions that people can take in the face of health disruptions (S. J. Williams, 2000). Management of symptoms as part of resources mobilisation, for example, can be used as a strategy to catalyse a sense of control and determine the acculturation strategies to be chosen later. This will depend on the potential to construct a sense of belonging and strangeness towards existing and new social relationships, with people who have physical disabilities or not. If physical symptoms are manageable, then self-identity can be constructed similarly to before, and biographical disruption should not take place.

The agency individuals can activate when coping with biographical disruption can be utilised to construct narratives that modify the meaning of previous experiences and their current interpretation. Not only do narratives provide order and control, but they also assist with the meaning assigned to that order. One practice of forcing control as part of biographical work can be a utilisation of acquired medical knowledge “to conceptualize the disease as separate from the individual self” (Bury, 1982, p. 172). Such perception, if possible, allows people to “hold the disease at distance” (Bury, 1982, p. 173) which may have a positive impact and as a result could lower the potential to develop a self-perception as a victim who fully bears the burden of responsibility over the hardships the illness causes (Bury, 1982).
People who undergo biographical disruption need to not only assign meaning to why they underwent this experience, but also to how it has impacted their lives and personality (G. Williams, 1984). Such interpretation must involve a new linkage between an unexpected present and a familiar past (G. Williams, 1984). In addition, such narratives address the fact that the order of things has been interrupted, and may question the link between causes and effects, in particular those that are relevant to body, self and society (G. Williams, 1984). In other words, narratives that are constructed as part of biographical work should be shaped both in order to understand a disruptive event in relation to past social experience and to reaffirm its impact on a present self (G. Williams, 1984).

One effect such a narrative can have involves a process of legitimation (Bury, 1991) that aims “to repair disruption, and establish an acceptable and legitimate place for the condition within the person’s life” (Carriacaburu & Pierret, 1995, p. 70). As such, it strives to maintain a sense of social value and reduce threats to social status in the face of a drastic health disruption (Carriacaburu & Pierret, 1995). This construction will also revolve, in the case of nonvisible health condition, around questions of with whom to share the diagnosis, how much to tell them, in what ways and in which contexts (Locock & Ziebland, 2015). These questions have to be answered based on people’s perception of their belonging and the subversion of a new potential strangeness.

Biographical work takes place within a particular context that impacts directly on an individual who experiences a health disruption. Different models of disability, for example, lead to different perceptions of what “disability” is. Though the central focus of this study revolves around health disruptions entailing acquired physical disabilities and chronic illnesses, it’s prudent to delve into various disability models for a comprehensive understanding of the broader experience of existing with a physical trait that complicates the process of harmonizing with society at large. This rationale underpins the selection of the social, affirmative, and medical models (expounded upon in Chapter 5) for examination and discussion. This approach ensures a well-rounded grasp of the intricate facets inherent in navigating such situations. Over the years, research has suggested three main models of disability: medical, social and affirmative. The medical model suggests that people with disabilities should be rehabilitated and treated for their disability and aspire to fit “able-bodied” society so they can operate as equals (Lindemann et al., 2017); this model will be further unpacked and criticised in Chapter 5.

The social and affirmative models of disability, however, take a different view of disability and, instead of adapting oneself to “normal” society, suggest exposing identity-oppression mechanisms, unpacking
the sources of stigmatisation of people with disabilities, and looking for social solutions that are based on notions of recognition, belonging and pride of people with disabilities.

**Social Model of Disability**

The social model of disability claims that biographical disruption is not the result of limitations caused by impairment or physical trauma, but instead is a form of “social oppression” (S. J. Williams, 2000) that has “nothing to do with the body” (Oliver, 1996, p. 42). Thus, the social model encourages changes in social settings so that people with disabilities or impairments are not disadvantaged in relation to both social and physical spheres (Burke, 2008). According to Shakespeare and Watson (2001), such groups are subjected to oppression by the dominant culture, which means that the sheer disadvantage of disability arises from the difficulties that are imposed on them and thereby has the potential to be deconstructed.

The social model’s basic assumption is that individuals’ ability to perform tasks and behaviours is dependent on the level of freedom they are given by dominant others in society. As the social model succeeds in de-medicalising disability it has becomes a valuable political tool for empowerment and social inclusion of people with disabilities and impairments (Palmer & Harley, 2011). It also challenges common stigmas that relate to individuals with disabilities and considers them unable to enjoy life, get married, become parents etc. (Barnes & Mercer, 2003).

As such, the social model of disability offers social change as the primary remedy for disabilities (Palmer & Harley, 2011), and challenges common stigmas that are related to impairment or disabilities. Goffman’s (1963) work on *social stigma* has contributed greatly to the development of the model as it focuses on social interactions between people with disabilities and people without disabilities, and reveals the practices of stigmatisation and exclusion. One of the dangers in stigmatising, Goffman claims, is that people may internalise the stigmas which are imposed on them. In such case “shame becomes a central possibility, arising from the individual’s perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing” (p. 7). In this case, people may accept the definition of their identity as “spoiled” while employing attempts to resist such classification (S. Fraser & Treloar, 2006). In fact, as biographical disruption leads individuals to filter their ideas and experiences through the mind/body self-consciousness (Peters, 2000) then it is almost impossible to ignore the stigma that is attached to the body. As such, constructing identification with “cultures of disability” may be complicated and problematic for people with acquired physical
disabilities (Barnes & Mercer, 2001). The levels of belonging construction, then, vary and impact the construction of social and political actions (Barnes & Mercer, 2001).

The social model of disability is based on the acknowledgement of a common culture that characterises people with disabilities worldwide. Cultures of disability, or disability culture as it is referred to by most researchers, was initiated in the 1960s by the Disability Rights Movement which challenged how general society disregarded the needs and rights of people with disabilities (Boyle et al., 2016). Later on, the movement led to political changes that were enforced by American law (Boyle et al., 2016). However, the term “disability cultures” appeared only in the 1990s when the different ways the term "disability" has been conceptualise in cultural contexts was first addressed (Borowska-Beszta, 2018).

Cultures of disability include different languages, such as Braille and sign language, and a variety of artefacts and symbols that are designed in reference to the body (Peters, 2000). Wheelchairs, canes and hearing aids, for example, are cultural artefacts that involve not only learning of new skills and behaviours, but also extract meanings for self-value and social appearance, and impact greatly on interactions constructed by individuals who are dependent on them. In fact, one’s negotiation of belonging and strangeness with cultures of disability would indicate an important aspect of self-identity construction that takes place as part of biographical work. In addition, further learning of skills can be related to relevant medical terminology and a new way of referring to the body. Learning the sign language, for example, can motivate negotiation of belonging with others who speak the language. However, individuals also learn how to relate differently to physical aspects: previously taboo areas of the body, for example, can be treated differently after a disruptive event (Peters, 2000) and may be subject to others’ control over them. That is, a person who acquires a physical disability that requires others’ assistance during intimate activities may feel that private areas of the body are exposed and expropriated by others. This would impact directly on interactions they have with other individuals around these activities, thereby belonging and strangeness negotiation.

According to Peters (2000), in order for people with disabilities to claim a disability culture and therefore a cultural identity, they should share a common language, a historical lineage, cohesive social community and political solidarity, acculturation (at an early age), generational or genetic links between members, and lastly pride and identity in segregation from others (Peters, 2000). This definition, in fact, can be applied to different cultures in other contexts, such as ethnic minority groups (Eddey & Robey, 2005). Furthermore, Barnes and Mercer (2001) claim that many individuals who identify as part of
disability communities refer to themselves as a cultural minority as they are likely to be excluded from general society. Therefore, cultures of disability can be defined as a new culture that individuals encounter within a unique type of acculturation process, as will be discussed in Chapter 9.

Despite that, it should be acknowledged that communities of people with disabilities are highly diverse and experience disability differently, according to their cultural context. In fact, Brown (2002) argues that is the most diverse known cultural group; however, the variety of cultural differences between its members may in fact challenge construction of belonging and solidarity between them. Having said that, individuals with disabilities usually share, according to the social model of disability, “a heterogeneous and multidimensional form in various parts of the world... [that] are subject to the regularities of the dominant culture” (Borowska-Beszta, 2018, p. 216). Therefore, cultures of disability include not only practices, artefacts, and values, but also the dominant culture’s perceptions of disability and how it affects the belonging negotiation of people with disabilities.

During the biographical disruption that results from physical disabilities, individuals inevitably encounter cultures of disability and respond according to:

Cultural repertoires that... [they] draw upon and fashion in presenting their altered physical appearances and social circumstances. Whilst this relates closely to processes of coping and strategic action, it brings into focus variations in the symbolic meanings, and social practices within different segments of the cultural order. (Bury, 1991, p. 462)

In other words, cultures of disability can be encountered for the first time after a health disruption, as individuals must develop knowledge and skills that will help to manage an unexpected and involuntary significant alteration of the body. This process takes place among individuals who, as part of dominant culture, may have learnt to stigmatise people with physical disabilities. That is, their initial perception of their biographical disruption and its implications will be negative in nature. However, while cultures of disability suggest encountering a stigmatised community, they also offer new potential for construction of belonging. According to Peters (2000), cultures of disability are “a thriving cross-cultural phenomenon which knows no national boundaries” (p. 597) and which is a basis for solidarity construction; furthermore, cultures of disability promote the development of hybrid consciousness for their members and rejects the way disability is viewed by the mainstream (Peters, 2000). These ideas were later
developed by the affirmative model of disability that calls for liberation of people with disabilities from their stigmas, and restores a sense of aesthetics and pride in their bodies.

**Affirmative Model of Disability**

Accepting the idea that disability is a social problem, rather than a physical problem, will not necessarily encourage people to identify with the community of people with disabilities. It is true that the social model was a steppingstone in the process of empowering people with disabilities in the political process of recognition (Barnes & Mercer, 2003); however, it perpetuates the view of disability as tragedy (Swain & French, 2000). The affirmative model, on the other hand, suggests that sometimes it is disability that enables people to escape other forms of oppression; Swain and French (2000), for example, interviewed a Malaysian woman with a visual impairment who was separated from her poor family and received better education than her siblings as she was sent to a “special school.” The affirmative model suggests that disability offers opportunities which are not available otherwise, such as the ability to develop compassion towards others (Swain & French, 2000). Clark (2012), in a research conducted with different stigmatised groups of youth such as refugees, youth with physical disabilities, and young people who identify as LBGT (Lesbian, Gay, Bisexual, and Transgender), suggests that they were able to protect their self-worth by attributing negative feedback from their surroundings to discrimination, and instead focus on their achievements in comparison to others from their own group. In fact, becoming stigmatised sometimes motivated the young interviewees to develop a political consciousness that helped them to construct a resilient self and to “grow as a person” (Clark, 2012, p. 98). It can be assumed, then, that this process was intertwined in developing a sense of belonging to a stigmatised group.

According to the affirmative model, cultures of disability provide opportunities for individuals with disabilities to break down feelings of isolation and offer empathy and acceptance (Galvin, 2003). As cultures are based on identification of shared understandings of common life experiences, they have the potential to encourage belonging construction that is based on familiarity, empathy and space for positive identity growth (Galvin, 2003). Such dynamics can contribute to individuals’ cultural competence as they learn to identify and support role models, develop coalitions for social change, learn skills of self-advocacy and reject imposed stigmas (Galvin, 2003). According to Brown (2002), people with disabilities share not only experiences of oppression but also a potential bond of resilience. They create art, music, literature, and other expressions of their lives and culture that are infused from
their experience of disability. They are proud of themselves and can be proud of their disabilities by charging them with a positive value as part of their identity (Brown, 2002).

Despite differences in how people with disabilities experience the world (such as hearing, visual, mobility difficulties), many have experienced discrimination that prevented them from participating as peers with equal rights and opportunities in civil society (N. Fraser, 1990). However, cultures of disability and the affirmative model emphasise pride of disability over shame, embarrassment and isolation (N. Fraser, 1990). Hahn (1993), for example, claims that disability can become an important source of empowerment and promote acceptance of human differences. That is, although disability begins as a difference according to definitions of others (who do not have disabilities), it later develops into equality, and ends with celebration of human differences (Brown, 2002). This is an aesthetic pursuit of the remodification of cultural schemas that comes to promote resistance to stigmatised bodies, and instead “cultivate[s] a heightened aesthetic appreciation of anatomical variations” (Hahn, 1993, p. 223). This view requires rejection of conformist visions of beauty and instead asserts that disability is beautiful (Peters, 2000). As such, people with significant acquired physical disabilities have more options than automatically internalising stigmas into self-identities, and as such have the potential to alter and develop their belonging negotiation. Moreover, this means that there is a possibility that alongside an undermined sense of control and trust, as well as shattered assumptions about the world and the self, individuals who undergo a biographical disruption are given the opportunity to experience an identity crisis that can lead to insights and self-development. These understandings transcend social reality, and offer an alternative social view of what could be, and not only what is.

From my point of view, the affirmative model does not rule out the hardships that are involved in managing a disability or an impairment. Thereby, it does not deny biographical disruption that results from shattered assumptions. However, the meaning that is attached to a disruptive event will not end with tragedy, as the affirmative model suggests a discourse of self-growth, development, and new opportunities.

**Summary**

Biographical disruption undermines a sense of control and trust because experiencing a nonelected event that prevents a person from constructing their self-identity as before will impact directly their belonging and strangeness negotiation—the focus of the next chapter. Biographical disruption involves a process of loss, of grief, and sometimes feelings of self-shame. These could undermine one’s sense of
control and trust that will directly affect self-identity construction and belonging/strangeness negotiation. The issue of control, the focus of Chapter 5, has been reviewed through the concept of perceived control. This concept offers a perspective that claims that a notion of control can stem out of factors that are not necessarily involved with the problematic issue (which individuals would not have control over); but at the same time the concept suggests that even an illusion of control has an impact that is similar to an actual ability to assert control over external world. In fact, it would be sometimes impossible to set a clear distinction between perceived and an actual sense of control.

A disruptive event would not only lead to biographical disruption, but also to biographical work. Within this process, individuals invest their resources to process, and to optimally adapt and reconcile self-identity during health disruptions. Construction of self-identity while utilising a “mental buffer” from illness is one example of this process, and of people’s agency during biographical disruption. Individuals have an agency and choice about how to construct their self-identity even when life circumstances are uncontrollable. Biographical work suggests that a disruptive event may have not only a negative impact but also a positive one. According to the affirmative model of disability, for example, disability is a symptom for the wide cultural diversity that humans construct, and as such it should be cherished and honoured. This should also be the perspective that navigates an understanding of the experiences of people with acquired physical disabilities. The next chapter will address further to issues of belonging and strangeness negotiation to better understand how self-identity construction is impacted by a disruptive event.
Chapter 3: Negotiating Belonging and Strangeness

Introduction

Belonging and strangeness function as key elements in the construction of self-identity. As such, they have a direct impact on individuals’ identity construction process. When individuals encounter a new culture, whether it is cultures of disability or other subcultures, cultural identification will revolve around negotiation of belonging and strangeness that can be modified during the continuous process of cultural contact, and will directly impact people’s biographical work as well as their self-identity construction.

This chapter will begin with the concept of “the other and “belonging” and strangeness” in regards to self-identity construction after a health disruption. It later discusses intersectionality theory as it is an inherent fracture of self-identity that is involved in belonging and strangeness negotiation. Intersectionality constitutes an integral facet of self-identity that demands recognition in the analysis of negotiations pertaining to belonging and navigating feelings of strangeness. This recognition is imperative due to the simultaneous coexistence of diverse intersectional identities throughout the process of self-identity reconstruction. In the context of this research, intersectionality’s scope extends beyond a narrow concentration solely on power dynamics governing the renegotiation of belonging and strangeness following health disruptions. Instead, it illuminates the realm of micro-level interactions, wherein intersectionality assumes a fundamental role as an inherent catalyst in the intricate process of reconstructing self-identity. These points of clarification are made within the thesis. Lastly, belonging and strangeness will be examined in the lights of two participants in this research and their relationships with a community of others with a similar physical condition to theirs. This would help to understand the ways intersectionality impacts belonging and strangeness negotiation and shapes self-identity construction after a disruptive event.
Belonging and The Other

Yuval-Davis (2004) suggests viewing the notion of belonging as an arena of dynamic identifications and participation that interface and help to understand the meaning and values people attach to their own identities and to others. She claims that belonging has three “facets”:

1. **Social locations**, such as people’s gender, class, race, nationality, physical condition etc.
2. **Identifications and emotional attachments** to groups as they are constructed through collective and individual narratives. This facet is relevant not only to existing social relationships but also to new ones that are formed during acculturation in different contexts.
3. **Ethical and political values** which are the ways these identifications are being judged, based on specific attitudes and ideologies which exclude others from becoming members of society. In a similar manner to cultural values that are offered by acculturation research, so does Yuval-Davis offer values as a tool for charging the negotiation process with purpose and meaning, which can lead to construction of belonging or strangeness. For example, belonging can be negotiated towards cultures of disability and communities of its members if they are grasped by an individual as groups that hold values of support and empowerment, acceptance, resistance to stigma etc.

The negotiation between belonging and strangeness is a complex interplay of these dimensions. For instance, belonging can be cultivated by aligning with groups that uphold values of acceptance, empowerment, and shared identity. On the other hand, strangeness arises when these connections and values are lacking or when one's characteristics are perceived as deviating from the norm. Yuval-Davis's exploration of belonging and strangeness underscores the intricate dynamics that shape individuals' sense of place within society and their interactions with various groups. Belonging and strangeness are complicated ideas that this research will attempt to decipher and unpack. Multiple components impact their negotiation, as will be detailed in Chapter 5, 6 and 7 of this dissertation, along the intersectional process.

Yuval-Davis (2010) claims that the other has a significant role in the process of defining the self. Psychoanalysis, for example, concentrates on the moment in which the infant acquires a sense of a separate self (Yuval-Davis, 2010). Yuval-Davis turns to Lacan’s theory of the “mirror stage” as “the moment of construction (which is) the moment of the realization of the separateness of self from m/other” (p. 273). During the mirror stage, Lacan suggests, a shift occurs as the infant’s relation to
themselves is mediated through an external object which is outside of the infant (Gallop, 1983). Hence there is no self, prior to the mirror stage (Gallop, 1983). The infant realises that it is separated from its mother, and becomes an object which is defined (desired) by the mother (Yuval-Davis, 2010). People not only construct their self-identity through the other, but they also understand themselves through the other (Yuval-Davis, 2010). Yuval-Davis (2010) refers to Bakhtin’s (1984) ideas about the other and claims that because people are able to understand how their self-identities are perceived by others, then they can conduct a dialogical process which evokes reflexivity:

To be, means to be for the other and through him, for oneself. Man has no internal sovereign territory, he is always on the boundary; looking within himself he looks in the eyes of the other or through the eyes of the other. I cannot do without the other; I cannot become myself without the other; I must find myself in the other; finding the other in me in mutual reflection and perception. (cited in Yuval-Davis, 2010, p. 271)

According to Taylor (1992), individuals aspire for recognition of their identities by other people as it has an intrinsic value for their dignity as human beings. That is, one constructs their self-identity in relation to the other on the basis of belonging and strangeness construction, which can be dramatically impacted after a health disruption. In this sense it should be asked how individuals who experience health disruptions would be interested in recognition of an intersectional identity that is related to a health disruption? And in what way, if any at all? As intersectionality is an important process of part of self-identity, it should also be considered as part of belonging and strangeness negotiation. In other words, belonging and strangeness should be examined through an intersectional lens: examining belonging and strangeness through an intersectional lens entails understanding these concepts not as isolated or singular experiences, but as deeply intertwined with various dimensions of identity and social positioning. Intersectionality acknowledges that individuals possess multiple identities—such as race, gender, sexuality, age, and more—that intersect and interact to shape their experiences and perspectives.

When we view belonging and strangeness from an intersectional perspective, we recognize that people's sense of belonging or feelings of estrangement are shaped by more than just a single aspect of their identity. Instead, these feelings are influenced by the complex interplay of different identities and how they intersect within different societal contexts. In this research, the analysis of intersectionality
directs its attention toward the intricate interplay among diverse identities that converge to shape an individual’s sense of self-identity, belonging, or strangeness. Unlike the conventional focus of intersectionality on power dynamics, the emphasis here lies on understanding how these multifaceted identities intertwine and contribute to shaping one’s perceptions of where they belong or not. This approach moves beyond the customary examination of power relations and instead delves into the complex relationships between personal identity and the experiences of belonging or strangeness within various contexts. Health disruption interrupts taken-for-granted assumptions that are related to one’s sense of belonging. Due to the fact that one cannot perform their identity as before such an event, a sense of “self-identity continuity,” as well as belonging, can be undermined during biographical disruption. This process will not necessarily take place in every journey of an individual that experiences a health disruption; however, at the very least one would have to renegotiate their belonging to cultures of disability, which complicates the self-identity construction process. In such case, a strangeness problem may occur as a result of stigmatisation, as mentioned in the previous chapter.

**Intersectional Identities**

To understand one’s social location on the sequence of belonging–strangeness, Yuval-Davis (2011a) uses a structure of intersectional identities which are “multiple axes of difference” (Yuval-Davis, 2006, p. 200) such as age, gender, race, class, professional and marital status, etc. as they are interpreted in the individual and collective levels. According to her, individuals choose to perform intersectional identities or silence them, according to specific socio-cultural contexts. This social process is used by individuals to construct an optimal sense of belonging and strangeness that helps them to construct their self-identities in relation to others.

The term *intersectionality* was firstly offered by women’s studies which claimed it is crucial to account for social positioning of a social actor, and reveal the social mechanism which leads to it as a result of power struggles (Yuval-Davis, 2011a). Crenshaw’s (1989) work on intersectionality, which relies on a proto-intersectionality body of work, calls for race and gender to be analysed as mutual and intertwined categories of the self (Cooper, 2016), and is credited with originating the term intersectionality (Cole, 2009); however, earlier Black scholar-activists have already claimed it is impossible to separate different race, class, or sex oppression, as in daily lives they are experienced simultaneously (Cole, 2009).

In fact, from the late 19th century, Black scholars and activists have theorised the relationships of intersectional identities and forms of oppression (Cole, 2009). Anna Julia Cooper (2016), for example,
urges Black male leaders to acknowledge a specific discrimination that Black women face. Beale’s (1970) later concept of “double jeopardy” of being Black and female (Cooper, 2016), is another example of an earlier work that was utilised to develop the rich theory of intersectionality that is known today. As such, the common ground on which early and later research of intersectionality is based was the practice of revealing social systems of oppression (Cooper, 2016). Intersectionality firstly focused on race and gender and rejected the “single axis framework” that did not count the interactions between identities that shaped people’s experiences (Nash, 2008). Later, other intersectional identities have been added and examined, such as class, gender, age, sex, religious, physical characters etc. (Cooper, 2016).

For intersectionality researchers, marginalised groups and individuals (such as people who experience a health disruption) hold an “epistemic advantage” that results from their social disadvantage and is utilised to shed light on the gaps between the existing society and a more just and accountable society (Nash, 2008). Another contribution of intersectionality is its aims to reveal the various social mechanisms, such as cultural, historical, economic, intuitional etc., that impact people’s identity construction and experiences (Else-Quest & Hyde, 2016).

Language, for example, has been examined as a social tool that creates social categories, rather than signalling them (McCall, 2005). This process of mechanism exposure allows intersectionality researchers to analyse how previous researches were biased and how the process of categorisation has led, eventually, to “demarcation, and demarcation to exclusion, and exclusion to inequality” (McCall, 2005, p. 1777). Having to come to terms with the concept “disability,” for example, and deciding whether, and how, to negotiate its incorporation into self-identity, can be problematic as it may lead to stigmatisation of other intersectional identities of the self.

Furthermore, intersectional theories have rejected the tendency to view social categories as essentialist and result of “biological destiny linked to differential genetic pools of intelligence and personal characteristics” (Yuval-Davis, 2009, p.50), and rather view them as socially constructed markers of difference between self and other, determining what is accepted and what is not, who is entitled to belong and who does not (Yuval-Davis, 2009). The notion of “ability” or disability, for example, involves vague and heterogeneous discourses, as people can be classified as disabled in a variety of ways that reflect political meanings and cultural contexts (Yuval-Davis, 2009). Charging disability with different values greatly impacts negotiation of belonging and/or strangeness. This is the process that sets social
actors’ positioning within the “politics of belonging”, and determines which identification can be developed by social actors.

People construct their belonging and strangeness based on their intersectional identities: to be a woman, for example, can be experienced differently by women who experienced a health disruption or not, Black women or White women, high-class or low-class, straight or gay, etc. (Yuval-Davis, 2006), as other intersectional identities affect the range of opportunities to construct belonging and strangeness with others. One’s intersectional identity, then, does not relate only to notions of belonging, but also to strangeness. That is, once the intersectional dimension of an identity is related to a certain context, the potential to belong should be examined, along with the potential to not-belong (that is, to become a stranger). This idea is closely related to Charmaz’s (1987) concept of identity hierarchy mentioned in the previous chapter: when biographical disruption takes place, individuals can select to perform one of many identities that compound the self to manage the impact a health disruption has on their life. This aspect of identities’ hierarchy is related mostly to identities that are impacted by bodily condition; however, similarly to intersectionality, it operates under power relations that motivate the construction of different levels of belonging and strangeness.

A health disruption, then, undermines belonging and initiates the requirement for identity work. As mentioned before, during health disruptions individuals design their strategies based on their motivation to construct belonging or strangeness towards different cultural groups. This process is based on an intersectional process that involves dynamics between intersectional identities of all participants in an interaction, and is catalysed by notions of familiarity (which provides potential for belonging construction) or unfamiliarity (which provides potential for strangeness). The operation of intersectional identities during interactions is dependent on individuals’ social agency and choice, as will be discussed in Chapter 7.

It’s imperative to understand that due to inherent limitations, it was not feasible to encompass all intersecting identities within the scope of this thesis. One particularly notable finding in the research is that the majority of participants chose to centre their discussions on their primary sphere of belonging, which, in many cases, revolved around their families. This emphasis on familial connections when addressing the consequences of health disruptions is a compelling observation. It highlights the significance of personal relationships and support networks in the face of health challenges. This choice made by participants also informs my approach to analysing intersectionality within this context.
recognize that their focus on family dynamics, while not directly related to traditional power dynamics, reflects a unique facet of intersectionality – the interplay of various identities and affiliations that shape individuals' experiences.

Exploring intersectionality takes on a crucial role in this study, particularly when the perspective shifts from solely examining power relations to a broader, more encompassing lens. Within the context of health disruptions, the relevance of intersectionality becomes even more evident. While my analysis in this study did not primarily centre on power dynamics, it is crucial to emphasize that this does not diminish the relevance of exploring intersectionality. Instead, it reinforces the idea that intersectionality extends beyond just power relations. It encompasses a wide array of factors, including but not limited to gender, race, class, and familial ties, all of which can significantly impact how individuals renegotiate their belonging and strangeness and navigate health disruptions. As mentioned above, given that the study's primary focus revolves around the negotiation of belonging, it was necessary to deliberately narrow the scope of analysis to a specific intersectional process. This strategic approach allowed for a more concentrated and refined examination of self-identity reconstruction after a health disruption. It is worth considering that future research endeavours could significantly contribute to a more comprehensive comprehension of the intersectional dynamics pertinent to the process of self-identity reconstruction following health disruptions.

Summary

A sense of belonging, as well as strangeness, is what impacts the intersectional process of the multiple identity that the self contains. A sense of belonging, as well as strangeness, can be shaped by social actors’ social locations and identifications and emotional attachments. These constructions would in fact lead to sense of belonging that is developed towards individuals’ set of believes and values. This could indicate why undermine of belonging can be so devastating at times: individuals learn to judge and estimate the social world according to set of values that relies upon bonds of belonging. Once one level (or more) of belonging negotiation is undermined, such experience may lead to biographical disruption.

After reviewing the different elements that impact self-identity after a health disruption, it would be a good time to reframe the research question: what are the conditions required for belonging negotiation, and what would trigger strangeness construction? A health disruption can stand as an example to provide answers for this research question. As a drastic change in life undermines existing circles of
belonging and strangeness, then renegotiating them will reveal the mechanism required for reconstruction of belonging and strangeness. However, it is firstly important to address the methodological design of this research, as it set a particular path for exploring this research question.
Chapter 4: Research Design

Introduction
This chapter presents the study design of this thesis and is structured in two parts. The first part of the chapter presents the study question and design, and outlines its theoretical and methodological commitments: intersectional theory and narrative research. These methodologies were selected as this research’s epistemology relies on constructionist principles. As such, it emphasises the importance of social actors’ constructions of meanings and interpretations. The intersectional approach of this research assumes inequalities and stigma attachment due to a health disruption. The focus of this approach did not challenge existing social structures, but reflected the interpretations that participants had about them and their agency during a life changing event. In addition, the intersectional process that was in focus was related to the relevant intersectional identities that were involved in an interaction that was led to negotiate belonging or strangeness. The decision to employ this intersectional approach is driven by the desire to comprehensively understand how individuals navigate social dynamics when facing health disruptions. By focusing on the interplay of intersectional identities, the research aims to capture the nuanced ways in which factors like gender, family roles, and age background influence individuals’ experiences. This approach allows the study to shed light on the complex interactions that lead to construction of a sense of belonging or strangeness, providing insights into the lived experiences of those affected by health disruptions.

The second part outlines the pilot and main study in terms of its research questions, recruitment, ethics in practice and data-collection processes. The pilot study took place in New Zealand and impacted greatly on the primary research that took place in Israel, my home country. In addition, this section presents a small portion of the analysis process that emerged from an exploration of belonging and strangeness as a result of a disruptive event, and later developed into the CSC model’s main concepts.

Part 1: Research Question and Design
The research question focused on the conditions that are required for belonging and strangeness negotiation after a health disruption. For this purpose the term “biographical disruption” was utilised to describe a drastic life change that can challenge self-identity construction as before. Biographical disruption, as mentioned in Chapter 2, suggests that an external event may lead to disruption in self-
identity construction. For the purpose of this research, then, it set a solid foundation to examine the conditions to renegotiate belonging and strangeness.

To address the research question, the initial research proposal of this thesis intended to explore people’s intimate social networks (such as family and close friends) and the process of belonging and strangeness negotiation that was shaped with their assistance. That is an important point because families who have been used to having a certain pattern of interaction between their members have to cope with changes that lead to reconstruction of sense of belonging due to a health disruption of one of their members. The principal idea was to locate this dynamic and later expand it to other interactions with other individuals during biographical disruption.

The original research was shaped by a holistic methodological approach, aiming to capture those small nuances that make up what is called “life.” I wanted to focus on people’s life stories in order to do what seems to be the impossible: not only to document the variety of interpretations people have about negotiating belonging and strangeness during different interactions they conduct after a health disruption, but also to elaborate on the chronological scope and identify other processes of belonging and strangeness negotiation in which they may have experienced in other contexts during their lives. Their stories would indicate the meaning they constructed about their experiences, their identity and interactions with others that may have been impacted by a health disruption.

Another question that was addressed at that stage was the focus group of the study. As discussed before, Bury based his research on chronically ill people, however this study wanted to focus on the experience of an acquired physical disability. As mentioned in Chapter 2, the division between chronic illness and acquired physical disabilities was problematized: first, as mentioned in Chapter 2, some of the participants in this research cope with disability that results from chronic illness (for example, multiple sclerosis [MS]); secondly, people with chronic illness may also continue their routine lives depending on their physical condition. When issues of visibility became an interest of this research at a later stage, the concept of health disruption was embraced as a framework to delve into how profound physical changes affect the way individuals navigate the realms of belonging and strangeness. Daniel, one of the participants, was selected to be interviewed despite the absence of a readily apparent physical alteration stemming from his health disruption. That is because the nonvisibility of his condition contributed to the understanding of identity construction after a biographical disruption in other
contexts. Details of the participant selection process, and an introduction to the participants themselves, will be presented later in this chapter.

Research Design

Following Crotty’s (1998) four components of a research design, I outline this study’s research design of epistemology (constructionist), theoretical perceptive (intersectionality), methodology (narrative analysis) and methods (semi-structured interviews).

Constructionist Epistemology
Epistemological assumptions provide justification for research design and indicate beliefs regarding the relationship between researcher and knowledge (Hiller, 2016). As mentioned, the purpose of this research was to investigate notions of belonging and strangeness after a biographical disruption; therefore, it was important to extract the meaning of these notions as they were constructed by the participants. To understand the experience of biographical disruption it was decided to utilise constructionist epistemology, as its point of departure is that in order to understand the social world, we should elucidate the world of meaning that individuals construct about their experiences (Schwandt, 1998). Constructionists, similarly to interpretivists, do not accept the naturalistic interpretation of the social world that positivism offers as it accepts only observable, measurable and empirical data (Schwandt, 1998). Instead, constructionist and interpretive approaches are interested in the human experience and the process of its mediations by social actors, and acknowledge that any data is constructed by "particular actors, in particular places, at particular times, fashion meaning out of events and phenomena through prolonged, complex process of social interaction involving history, language, and action" (Schwandt, 1998, p. 222). They claim that both reality and knowledge are constructed through communication, interaction, and practice (Tracy, 2013). As such, human activity is not regarded as an empirical reality that should be discovered and measured but is considered as a text that can be “read, interpreted, deconstructed, and analysed” (Tracy, 2013, p. 41) and can incorporate contradictory perspectives.

As such, constructionists investigate constructions or meanings about broad and general concepts such as cultural values, or more specific social issues or ideas (Williamson, 2006). For the purpose of this research constructionist epistemology is utilised to unfold the experience and meaning making of biographical disruption and the challenges it presents to continuity of self-identity construction, which are operationalised by belonging and strangeness negotiation. Assuming biographical disruption is a
subjective event that may be experienced differently by individuals, constructionist epistemology accepts the potential of multiple realities’ co-existence (Kelly et al., 2017).

Constructionists are committed to the perception that comprehends that what is considered to be objective knowledge is in fact a result of perspective (Schwandt, 1998). Knowledge and truth, according to them, are created and not discovered (Schwandt, 1998). They emphasise the construction of reality and the instrumental ways it is deciphered by individuals, and claim that “contrary to common sense, there is no unique ‘real world’ that pre-exists and is independent of human mental activity and human symbolic language” (Bruner, 1986, p. 95).

**Social Actors and World**

According to this epistemology, the mind is active in the process of construction of knowledge (Schwandt, 1998). Furthermore, Schwandt (1998) suggests it is easy to accept that the mind does something with the impressions it collects, and at the very least forms abstractions or concepts. Therefore, individuals invent models, ideas and schemas to make sense of their experiences and test these constructions further in light of new events (Schwandt, 1998). The interpretative process that constructionists rely on is intended to untangle the meanings people construct rather than providing an explanation of causes and effects that can be identified by distant and pseudo-objective observation (Hiller, 2016). In fact, from a constructionist perspective, social reality is manifested by the meanings people ascribe through individualised perceptual schemas that are context bound and independent of natural laws (Hiller, 2016). Schwandt (2003) refers to constructionist epistemology as a form of perspectivism, which is individuals’ experiences are given phenomena that are intermediated through a particular lens. In other words, “there exist neither value-neutral perceptions nor singular, permanent truths” (Hiller, 2016, p. 112). Instead, all perceptions and impressions are subjective and immersed in their context.

By focusing on meanings that individuals produce, both interpretivists and constructionists relate to human agency and its manifestation in everyday life. In a similar manner to interpretivists’ view of agency, constructionists support the presumption that social actors are considered autonomous, intentional and goal directed (Schwandt, 1998). Moreover, their ethical principles do not approve “the elimination of judgement on the part of the decision maker” (Schwandt, 1998, p. 229). Constructionists celebrate the importance of agency during the construction process; however, at the same time do not ignore the cultural structure that impacts the scope of choice that is available to individuals.
**Interpretation of Texts**

As mentioned before, according to constructionist epistemology, the process of analysis of cultural texts requires understanding the meanings that a situation holds for individuals, not only their behaviour (Hiller, 2016). However, gaining access to the meanings constructed does not indicate that the researcher can get to an intimate form of psychological closeness that could lead to a sort of transcultural identification, according to Geertz (1983). Rather, knowledge that is gathered through qualitative methodologies may yield an understanding that “unfolds as one looks over one’s respondents’ shoulder at what they are doing” (Schwandt, 1998, p. 231).

An idealist epistemology constructionism promotes a pluralistic and relativist frame of reference as there are multiple constructions of meanings that may often be contradictory, and all can hold an equal value in the epistemological sense (Schwandt, 1998). In other words, constructionist epistemology could claim that no interpretation is more valid over another and no interpretation is a definitive one (Hiller, 2016). Furthermore, as Schwandt (1998) points out, the findings of any research are themselves a product of construction of the methodological process. It is bound with the context of a specific cultural structure, and is the result of constructions that the researcher forms, which are in principle subjective and contextual. The researcher brings their own world of beliefs and experiences to the data gathering and analysis process; thereby knowledge, according to this hermeneutic process, is co-created or intersubjective as it evolves out of the interaction the researcher has with the participants and research data. As such, the researcher must develop self-reflective awareness of their own constructivist process (Schwandt, 1998).

**Criticism of Constructionist Epistemology**

From this perspective, the notion of understanding is subjectively constituted and researchers may come closer to deciphering others’ interpretations; however, at the same time, this means that a full and comprehensive understanding is not achievable (Schwandt, 1998). As mentioned before, knowledge is not discovered but constructed independently of the world “out there” (Schwandt, 1998). The difficulty this assumption creates is that knowledge is a form of a theoretical production that is assumed to be transferred between individuals. However, how is it possible to account for one’s original meaning and the meaning constructed in another individual’s mind? If constructions operate within individuals’ subjective minds how can it be assumed that their outputs are not altered by other individuals? One way to resolve this problem would be to emphasise the cultural and social construction of knowledge.
(Schwandt, 1998). That is, one would need to address the social and cultural structure in which knowledge is constructed and analyse subjective constructions accordingly (Schwandt, 1998). Another solution, as mentioned before, would be to accept that knowledge cannot be created without construction processes. In other words, constructionism or interpretivism should be accounted for not as epistemological or methodological views but as the basic condition of human inquiry itself (Schwandt, 1998).

This discussion, however, does not resolve a fundamental problem of this epistemology: considering a person’s perspective during an interview, for example, means that in a Cartesian sense there is no actual grasp in reality (Hiller, 2016). This issue becomes even more crucial in disability studies, for example, as “the role of certain interpretations and discourses in mystifying reality is vital” (Iosifides, 2018, p. 102). In other words, those who construct others as discriminatory would construct an interpretation of the social world as a world that is contaminated with prejudice. But is this always the case? Does every experience that is interpreted by a social actor as discriminative result out of albeit intentions of others?

Another problem is that some of the constructions that are relevant in these studies can be objectively false; however, they still impact in an authentic way on objectively true conditions of power relations (Iosifides, 2018). Stigma, for example, is a set of interpretations that relies on biased assumptions about self and others and is linked to actual power relations of domination and exploitation (Iosifides, 2018). As such, it directly impacts belonging renegotiation, despite the fact that it is based on biased, and in fact wrong, assumptions about other cultural groups. This is essentially a relevant claim for any social qualitative research and therefore it is reemphasised that social reality is not natural in the way that it exists outside of the human mind.

These ideas lead to another problem in the absence of a set of criteria for validation: how can subjective constructions be accounted for as knowledge? In other words, “what is an adequate warrant for a subjectively mediated account of intersubjective meaning? (Schwandt, 1998, p. 246). A partial solution would be to mitigate the constructionists’ claim that all constructions are equally “good or bad, worthy or unworthy, true or false, and so on” (Schwandt, 1998, p. 246). As such, the researcher must make qualitative decisions that rely on his/her own subjective construction (Schwandt, 1998). The researcher’s intuition is what stands at the base of the claim about truth, worth, or value that develops the construction of the research (Schwandt, 1998). As there could be multiple explanatory claims about different social phenomena, it has to be acknowledged that researchers represent only one option of
many to understand the world (Schwandt, 1998). In addition, the researcher in this type of research holds an obligation to provide a detailed and thick description of the relevant contextual information (Hiller, 2016). Throughout the researcher’s self-reflective process of conducting and analysing the research, the purpose of thick description is not only to invite the readers into their construction of research, but also to expose “behind the scene” processes and subject the research to an effective external criticism. This point stands also to emphasise that qualitative research is from a particular and time-bound communication interaction between the researcher and the participants (Iosifides, 2018), and as such should address its contextuality and provide relevant information that would reveal potential biases.

To conclude, interpretation of individuals’ texts is almost always biased, lacking and subjective. However, they hold an inherent value in the human research process and are irreplaceable in an epistemological sense. They hold a unique form of agency that is developed out of a previous cognitive process, and impact not only the research, but also the researcher.

**Theoretical Perspective—Intersectionality**

Intersectionality was one of the first theoretical frames that was utilised for understanding belonging and strangeness for this research. I first learnt about the theory from Yuval-Davis’s (2007) “politics of belonging” that revolves, as mentioned in the previous chapter, around the notion of identity construction of the self and of the self of the “other”. Power relations, more specifically, between aspects of individuals’ identities, are involved in the process of belonging and strangeness negotiation of social actors (Yuval-Davis, 2007).

Intersectionality theory provided both an advantage and an obstacle to this research; as it revolves around self-identity construction based on belonging and strangeness negotiation, it provides an in-depth understanding of power relations between social actors; however, “the theory is not a falsifiable theory in the positivist sense of theory” (Else-Quest & Hyde, 2016, p. 159) that can measure, estimate and compare the dominance of a given intersectional identity, but rather functions as a critical theory that is aiming to discuss power relations and oppressions (between and) of different intersectional identities. This research encounters a comparable challenge, as it delves into the realms of belonging and strangeness, two concepts that are notoriously difficult to measure and conceptualise. In other words, while the research pivot does not mainly focus on power dynamics to exploring the realms of belonging and strangeness, the essence of intersectionality still retains its non-positivist nature,
rendering the quantification of these intricate concepts problematic. It’s worth highlighting that despite its departure from a positivist stance, intersectionality presents a valuable avenue for comprehending the enactment or absence of diverse identities within micro-level interactions. However, the persistent obstacle of quantifying abstract concepts remains a notable challenge.

In fact, intersectionality researchers ask whether there is any coherent methodology that may capture and represent the essence of all multiple divisions that compound self-identity (Cooper, 2016). In that matter, intersectionality researchers are occupied with the question of how many social categories are (or should be) involved in the analysis of intersectional processes. In other words, is the number of categories in the self is limited? (Yuval-Davis, 2009). According to Butler (1990), the “etc.” that usually appears at the end of social categories lists is an embarrassed admission of a “sign of exhaustion as well as of the illimitable process of signification itself” (p. 143, cited in Yuval-Davis, 2006, p. 200). Instead, the process of signification of the self is “illimitable”; however, particular historical contexts trigger construction of specific categories that establish a different grid of power relations (Yuval-Davis, 2006). For that matter, intersectional theories can reveal the mechanisms that motivates social actors’ behaviour as it deals with their identity construction.

This research examines the potential to construct strangeness or belonging as the basis for self-identity construction. More particularly for this research, an intersectional process takes place when individuals mobilise (or not) intersectional identities that are related to health disruption, regardless of how such it has been acquired, and these intersectional identities can be related to another individual’s intersectional identity. The presumption is that interactions that could have triggered mobilisation of a health disruption intersectional identity would not necessarily lead to it, as mobilising this intersectional identity may lead one’s identity to be positioned in an undesired strangeness in relation to others. In addition, as mentioned in the previous chapter, not all intersectional identities of the participants in this research were examined as the focus is on intersectionality of a health disruption that involves biographical disruption. Intersectionality theory, therefore, was used to understand the mechanism of renegotiation of strangeness and belonging in relation to the biographical disruption context, and therefore focused on the most relevant intersectional identity that is related to health disruption.

Intersectionality should be embraced as a critical theory rather than a theory that claims to reflect all aspects of intersectional identities and the ways they are experienced. In that matter, intersectional complexity is relevant not only for social categories, but also to “contextual dynamics of interpretations
that are themselves intersectionally constituted” (Cho et al., 2013, p. 789). That is, the intersectional process itself is constructed through intersectional lenses that lead to an interpretation that triggers the process of further intersectionality. This text, for example, is dictated by my own intersectionality as I am composing it now, as well as the intersectional identities that were utilised by me during the interviews that were conducted with the participants. However, that is not the last intersectional aspect of intersectionality: Cooper (2016), for example, calls for a clear distinction between a personal kind of identity and structural identities. For if the law conceptualises people through structural identities (gender, age, race, sexual orientation, national origin etc.) then another way would be to examine people’s personal identities that refer to personal taste, personality characteristics, gender performativity, or socially intimate relationships (Cooper, 2016).

This notion elevates the concept of intersectionality to processes of social interactions, in which people’s habitus (and as a result their collective belonging and strangeness) is continuously constructed. This point is important for this research as intersectionality does not only display the process that the participants went through during biographical disruption, but also the ways in which I have shaped, designed and interpreted this research.

**Methodology - Narrative Analysis**

People who experience biographical disruption as a result of a health disruption during adulthood may find a need to construct a narrative that explains what caused it and what the meaning of the new condition is. Bury (1997) claims that while there is a need to define the impact of health disruption on an individual’s daily activities and relationships, there is also a need to understand its cultural and symbolic significance (Barnes & Mercer, 2003). For this reason, it would be relevant to relate to the concept of “disability” and the way it is defined by people who experienced a health disruption as well as to the way their social surroundings construct it over time. Although people were interviewed more than a year—and in most cases a number of years—after a health disruption, the focus of the interviews included the immediate period after the event and aimed to portray the process of belonging negotiation over time.

Narrative studies, according to Tuval-Mashiach et al. (2004), can reveal the means by which people shape their world view and design self-identity. Narrative research is especially interested in story telling as a method for understanding self-identity construction as it relies on people’s interpretation and
meaning making of events (Josselson & Lieblich, 1999). Every story, Josselson and Lieblich (1999) suggest, should be examined according to the following questions:

- Who was the story constructed for?
- Under which circumstances was it constructed?
- What discourses does the story rely on?
- What is the purpose of the story?
- What cultural tools are used to construct it?
- What meaning does it strive to construct?

When relating to a change or transition period that affects one’s self-identity, it would be useful to explore the way the constructed narrative attempts to reconcile (sometimes unsuccessfully) different self-identity components that are adopted or rejected during this period. Narratives, life stories and biographies are always constructed in a particular cultural context (Bruner, 1987): they represent cultural models, norms, language, and values that narrators identify as part of their self-identity. Story telling can be used, in this sense, to construct belonging and strangeness by drawing a line between the narrator’s collective identity and “the others.” Stories are rich in details and therefore are not short sections of narratives. The stories provided by the participants in this research stand for the meanings that they construct about their self-identity in regard to an acquired physical disability and belonging and strangeness negotiation.

Smith and Sparkes (2008) rightfully argue that narrative research is particularly useful in relation to health disruptions as it can reveal the social forms that construct people’s identity as disabled or impaired. In addition, since “bodily experience is deeply embedded in narrative” (p. 19) such method can help to understand the ways in which people interpret, give meaning to and understand the changes that their identity goes through as a result of a health disruption. As such, narratives of people who experienced health disruptions can challenge other discourses that relate to disability simply as tragedy or deviance (Smith & Sparkes, 2008). They are also able to challenge other stereotypes of them as pitiable, for example, tragic but brave, passive or one dimensional (Cameron, 2007). Such narratives could resist general representations and assumptions that rely on the idea that disability has no desirable attributes (Cameron, 2007), and instead focus on concepts of joy and happiness in disability, as Sunderland et al. (2009) suggest, or at least address its complexity.
The mechanism of narrative construction is an important concept for this kind of research. For example, Ochs and Capps (1997) ask how memory affects the story design, and, furthermore, how the accuracy of the memory can be ascertained. Elsewhere Ochs and Capps (1996) claim it is not the complete self-identity which is performed through the narrative, but merely bits and pieces of the self which the narrator wishes to display. Despite that, the current research suggests that people provide not only accounts of what has happened, but of their interpretation of it. Therefore, the bits and pieces that are provided by narrators are not randomly picked, but carefully selected as they aim to portray a coherent culturally contextualised picture of events, and for that purpose can relate to a particular cultural knowledge and positioning of the listener.

Narratives function as a tool to construct identities: Toni Morrison notes that “Narrative is radical, creating us at the very moment it is being created” (p. 161, in Ochs & Capps, 1996, p. 22). That is, verbally designing one’s stories during an interview is in itself a construction process of self-identity. Furthermore, telling and retelling, according to Flannery O’Connor, contribute to “new ways of seeing, saying and thinking about what it is that... (we try) to understand” (in Ely et al., 1997, p. 20). Atkinson and Silverman (1997), on the other hand, claim that “the self is rehearsed” (p. 314) and rather than considering the interview as a spontaneous performance and authentic of the self, suggest viewing it as a repetition of external discourses. This research would claim that while it is true that individuals’ choices are linked to cultural knowledge that they hold, it should be acknowledged that social interactions do involve more than one individual, and that would impact self-identity construction in an unexpected way; therefore, the interaction that is involved in conducting semi-structured interviews cannot be classified as deterministic. Having said that, interviews stand also for a particular type of interaction that allows individuals to reassert their self-identities as they become “the subject and the object of the narration” (Atkinson & Silverman, 1997, p. 315). However, whether self-identity is a product that is constructed by cultural conventions and/or upon the context in which the story is told, it is always fraught with personal and social meanings that are selected by the narrator and therefore are valuable.

The narrative analysis that is offered within this research is, of course, not complete. Other research questions could have led to construction of other meanings and interpretation that were provided by the participants. The meanings that were constructed as a response to this research’s questions, then, and the subjective reference point of the researcher, yield a particular analysis that is lacking in some
respects, but can contribute to general understanding of the processes of strangeness and belonging negotiation.

This research focuses on stories of people who experienced health disruptions as they reflect on their identity construction process before and after it, and during the time of the interview. However, in a few cases, aspects of participants’ identities that are not directly related to a health disruption became relevant as part of understanding the process of self-identity construction on the basis of belonging and strangeness negotiation. For example, one participant’s intersectional identity that is related to their sexual orientation has been the centre of one of their narratives, which demonstrated very well the dynamic of CSC factors and intersectional process (discussed further in Chapter 7), and thereby was chosen to be included in the final thesis.

This method has been chosen based on the assumption that individuals are able to assist with integrating different experiences into one coherent whole and utilise narrative construction for doing so (Palombo, 1994). As mentioned before, narratives can help people to reconcile conflicting experiences or self-identities. As life stories are able to link between past and future expectations, they also reflect the narrator’s present viewpoints (Rosenthal, 1993). In fact, according to Spira and Wall (2009), when people produce a relatively coherent life story, they are able to construct a sense of meaning even if a health disruption took place during their lives. The dynamic of different aspects of self-identity (and intersectional identities) before and after a health disruption, and the way it would be reflected by construction of a particular narrative, have the potential to contribute to the understanding of how people renegotiate their belonging and strangeness during their lives.

**Methods—In-Depth and Semi-structured Interviews and the Role of Narrative Inquiry**

Data collection for the original research included multiple in-depth and semi-structured interviews with people who experienced a health disruption. This methodology was selected as a study that is designed around narrative research can promote intersectionality’s objectives: according to McCall (2005), narratives focus on individuals’ experiences and aim to extract them to the broader relevant social location.

By giving voice to different individuals and groups, researchers hope to deconstruct the original dimensions of social categories and expose their artificiality (McCall, 2005). The problem, according to McCall, is that “individuals usually share the characteristics of only one group or dimension of each category defining their social position” (p. 1781). As a result, the intersection process portrayed is of a
single dimension of each category; in other words, the “multiple” components that intersectional analysis refers to is the variety of categories, rather than dimensions within categories (McCall, 2005). As mentioned before, this research attempted to develop a further understanding of intersectional dynamics by positioning an intersectionality that is related to health disruptions versus other intersectional identities that are available in a specific context. For example, one participant chose to maintain an intersectional identity of her social role as a mother, rather than mobilising her health disruption and addressing its needs. This does not solve the issue of multiple axes of intersectionality; however, based on the theoretical ideas Yuval-Davis offers in the *politics of belonging* (2004) this research aims to provide a better understanding, not only of the way people’s agency is applied to construct and perform intersectional identities after a health disruption, but also why they do that.

As such, this research acknowledges that personal narratives may aspire to portray the full picture of social relationships and cultural conditions that define social locations and categories; however, that is mostly not possible as narratives usually reflect only fragmented aspects of memory and therefore the intersectional process (McCall, 2005). Narratives, then, provide rich data that originates from a single subjective interpretation, rather than data that is constructed “at the intersection of the full range of dimensions of a full range of categories” (McCall, 2005, p. 1781). The aim of this methodology is to collect narratives that indicate the challenges of (re)constructing belonging, or dealing with becoming a stranger after a health disruption. The meaning that people give to their social positioning, collective identity, and social interactions should be carefully extracted from the interviewees’ words for that purpose. Therefore, multiple semi-structured interviews allowed participants to craft the meaning they wished to give to their experiences. The interviews, in that matter, functioned as an activity that reflects the process of constructing self-identity which unfolded before the eyes of the researcher.

**Summary**
The purpose of the epistemology chosen, theoretical perspective, methodology and methods was to extract the meanings in participants’ construction about biographical disruption, renegotiating belonging and strangeness, and thereby understand the self-identity construction process.

As constructivists emphasise the construction of the social world, this research will examine if constructions that refer to biographical disruption correspond with constructions that reflect the acculturation process. The path chosen to investigate this question was, as mentioned, to give voice to individuals who experience events that challenge self-identity construction. Constructivists do not
ignore cultural structures that help to design individuals’ schemas and interpretations, but at the same time emphasise the potential people have to choose their behaviour and meaning construction, that is in fact one of many options to activate their agency. In addition, constructivists also do not ignore the researcher’s subjective constructions that direct research design, development and interpretations.

As health disruption may undermine individuals’ sense of belonging and enhance experiences of strangeness, it is important to address a discourse of discrimination, stigma and “otherness” that involves the lives of the participants in this research and other social actors who experience disruptive events in a variety of contexts. By addressing the intersectional process, it is possible to examine situations in which individuals mobilise (or not) intersectional identities that are related to stigmatised groups. That sheds light on management of unequal power relations that take shape after a health disruption, in light of belonging and strangeness negotiation. In fact, the understanding of this process could be expanded to other intersectional identities in the context of transition.

The pilot study and main research were designed around narrative analysis as this methodology supports both constructivist and intersectional presumptions. Suggesting in-depth understanding of a selected topic ensures that a small number of participants can provide rich data about their experiences and the complexity of the object of study.

**Part 2: Pilot Study New Zealand and Main Study in Israel**

**Pilot Research in New Zealand**

The pilot study of this research included three primary participants who experienced a health disruption and have been coping with it for at least 1 year. This period of time was assumed to provide the opportunity to incorporate their physical change into their self-identity construction process and give them insights into their belonging and strangeness renegotiation strategies. In addition, primary participants had experienced an unexpected health disruption during adulthood which was been set to 25 years and above. I chose this age because it is assumed that by this time a person has constructed an adult identity before a health disruption.

Primary participants in New Zealand were asked to nominate people who are part of their intimate social network that might consent to participate in the research. Secondary participants were asked to consent to participate in the research and be interviewed as well. Each primary participant suggested two secondary participants who, ideally, would have been interviewed several times for the purpose of
this research about primary participants’ biographical disruption experience. It was suggested to conduct multiple semi-structured interviews with primary and secondary participants to try to gain a more holistic depiction of events and meanings in the process of self-identity construction after biographical disruption. The research protocol, as well as the following procedures, received the approval of the ethics committee of the University of Auckland (Appendix A).

**Recruitment**

Third-party recruitment method was utilised for this research, and specifically local New Zealand organisations for people with disabilities, such as Deaf Aotearoa New Zealand, National Foundation for the Deaf, The Association of Blind Citizens of New Zealand, Disabled Persons Assembly and more. Administrators received a detailed explanation about the purpose of the research, the methods, and the objective to interview people who experienced health disruptions, along with two members of their family and/or close friends, and transferred this information to potential participants. In the event a potential participant was interested to receive more information about the research or the researcher they were able to contact me directly via email.

**Semistructured Interviews**

Abma and Stake (2014) call for a naturalistic approach that focuses on the particularities of the case study. Case study, in this respect, utilises naturally occurring sources of knowledge, such as observations of interactions that take place in the physical space (Hyett et al., 2014). However, since this research focuses on individuals’ construction and interpretation of an experience that involves negotiation of subjective terms (such as belonging and strangeness) it was methodologically more appropriate to conduct semi-structured interviews in order to understand the participants’ viewpoints and meaning construction of this process. In this respect, participants in this research are perceived as the experiential expert on the subject (Smith & Osborn, 2009) and the data they provided was used to establish theoretical ideas that this research offers.

Semi-structured interviews were selected as a method, along with narrative analysis. Despite the fact that such methods yield rich and complex data it is acknowledged that they are limited in the scope of intersectional process that they represent, as not all intersectional identities of self-identity are reflected in the following narrative analysis, hence it cannot claim to represent the complete self-identity construction process.
This research focuses on stories that narratives stand for. The stories include participants’ interpretations of the self and of the other, as well as the power relations between them, and are of particular importance for disability studies. In the following pages, I will offer analysis development of the theoretical ideas of the research, along with the methodological changes that took place as result of the pilot research.

Semi structured interview method has been selected also because it may facilitate empathy between researcher and participants, allows malleable development, and produces rich data (Smith & Osborn, 2009). The role of the interviewer in such a method is to facilitate and guide the event, rather than dictate it (Smith & Osborn, 2009). Although this form of method reduces the level of control that researchers have over the research process (Smith & Osborn, 2009) it is a useful method for triggering flexibility and creativity as the researcher is occupied with the data provided and its meaning for the research, which supports development of both interview protocols and theoretical thinking.

The primary participants’ interviews revolved around identity issues; the changes they experienced in relation to their professional identity, social networks, residence status, hobbies and skills; aspects of previous self-identity that were missed or not; new social roles they may have adopted or old ones that were lost or rejected; social affiliation to the disability community and its impact on self-identity construction; and experiences of discrimination. Secondary participants were asked to describe the primary participant before and after a health disruption (characteristics, behaviours, skills and social roles) and the changes in their relationship with the primary participant. I was wondering how belonging renegotiation after a health disruption would impact the dynamics in a social network rather than in one individual’s narrative only. The mixture of differences in identity, social roles and interactions could indicate strategies for reconstruction of belonging and ways to cope with strangeness.

Eventually, the pilot study in New Zealand included only two primary participants, three secondary participants, and a total of 10 interviews. The main problem identified at that point was their roles in primary participants’ life stories. Inspired by my own acculturation journey from Israel to New Zealand, I attempted to refer to secondary participants’ stories as a reflective process of “receiving societies”. In fact, the original research aimed to find parallel points between acculturation processes and the experiences of primary participants as they respond to a new intersectional identity (that is related to a health disruption) that sets them in a new context. In such case, secondary participants would function as a new type of a “receiving society”. However, societies become “a receiving society” when they begin
to interact with newcomers. The latter’s entrance has the potential to change the social texture of a receiving society as the dynamic with new social actors begins. However, in the current research the case was not of a social community who had new members joining it, but rather a social structure with members who experience a significant physical change that impacts their social roles. The dynamic between primary and secondary participants before, during and after health disruption was indeed related to constructions of belonging and strangeness but was not qualified for addressing the dynamics between immigrants and receiving societies.

**Ethics**

Participants received an abstract of the research question along with information regarding the purpose of the study, the methods and length of time which they would be asked to contribute to the research. After being nominated by primary participants, secondary participants were contacted and provided with information about the research in order to receive their consent about participating in it. All interviewees were asked to approve audio recording of the interviews in advance but were also informed that they could refuse to be recorded. All names and identifying characteristics (such as residence area, place of employment, etc.) are not mentioned in this thesis. Instead, pseudonyms are used, and there is no reference to identifying characteristics of the participants.

As the community of people with physical disabilities could be socially marginalised and therefore might have limited access to social rights and power, it was relevant to address the possibility that some of the participants would have seen themselves as part of a vulnerable group. This issue is related to the notion of power relations between the researcher and interviewees, especially when the researcher is a person without a significant health disruption. As such, the researcher must develop an awareness of any imbalances between social relations, and thereby promote a sense of control for participants, for example by inviting them to set the time and place of the interview, determine withdrawal from the research at any point, receive transcriptions of interviews and comment on them if they wished to do so.

Secondly, the pilot study took into consideration that primary participants might have preferred to conduct joint and/or family interviews, in addition to individual interviews. Such form of interviews has multiple ethical implications that must be considered. One benefit of such interviews is that confidentiality between primary and secondary participants might not be a consideration, as both types of participants attend the interview. However, there are emotional risks associated with such form of
methodological process, both between the researcher and the interviewees, and between the interviewees (Boss, 1987). For example, the interview can generate information that the family or close friends have not yet dealt with, or which might make them feel discomfort (Astedt-Kurki et al., 2001). Furthermore, different views can be discussed, but sometimes will even be argued (Donalek, 2009). Although researchers may provide information or emotional support during interviews and joint interviews, it was important to note that I have no practical knowledge to assist participants, and instead was prepared to advise them to consult practitioners by providing a list of relevant professional providers in advance. Having said that, I acknowledge that the researcher must be aware of how the participants feel when the interview is finished and cannot leave without offering any support (Donalek, 2009). This information appears in the participant information sheet (PIS) of both primary and secondary participants (Appendices B and C). In addition, I offered to conduct a meeting with both primary participants and their two nominees prior to research interviews, in order to verify that everyone was feeling comfortable with the process of the research, and answer any questions they might have had.

**Pilot Analysis**

The pilot analysis required to extract the meanings that participants carved into their stories. The first step was to understand events of strangeness and belonging as the arenas for self-identity construction, and unpack the way participants interpreted these events. When participants portrayed events of feeling misunderstood, mistreated, distressed by actions of others, or seeking for isolation, it was an indication of the process that their self-identity, as well as their networks of belonging, were going through. These events were an indication of belonging and strangeness negotiation, either by an active behaviour, constructions of interpretations or other forms of agency.

A methodological challenge was related to my subjective constructions of the participants’ meanings; as my personal acculturation journey in New Zealand involved many hurdles and, as a result, I experienced strangeness, there was a risk that I would refer to the participants’ experience of biographical disruption from a stranger’s perspective, and be biased towards narratives of strangeness and rejection. However, my own immersion in the context of transition led to a development of intimacy with the data collected (Eisenhardt, 1989) and reflexive understanding that enabled me to recognise flaws in my initial presumptions (Van Wynsberghe & Khan, 2007).
This self-awareness process led me to focus on dimensions of belonging and strangeness and search for discomforts in the process of their negotiations. My personal experience of strangeness correlated with the disruptions of my self-identity construction during the time I spent in New Zealand and that led me to seek similar challenges that the participants had to manage due to biographical disruption. However, shortly after conducting the first interviews it came to my knowledge that my struggles were impacting my methodology and interpretations of the data collected. In fact, I was referring to my acculturation experience as a hypothetical case study that was linked to the research question. As a result, as suggested by Eisenhardt (1989), subtle similarities and differences came across not only in participants’ experiences but between my own story and theirs. Having said that, as mentioned before, my self-awareness about potential subjective bias did not prevent the development of theoretical ideas that are offered by this research. Despite the fact that my personal view of the research topic is evoked by subjective experience, it does not mean this view is not valuable. Instead, the theoretical ideas of this research should be examined for their relevance also to individuals who managed to establish a stronger sense of belonging.

**Strangeness**

Natalie, an MS patient in her 60s, depicts her social life and the way it changed a few months after her diagnosis and loss of her job as a department manager. She refers to a social world that was getting more and more narrow as a result of the MS. In an intersectional sense, or cultural sense, she is describing a universal phenomenon. Every person can withdraw into themselves, regardless of their cultural contexts. In this sense an intersectional framework is also questionable for the pilot analysis. The main aim is to acknowledge belonging and strangeness negotiation as universal phenomenon. The particularity of each narrative is indeed important, however during the pilot study the importance of the core elements of belonging and strangeness as human experiences were the focus. Going back to Natlie’s narrative, it comes to reconcile the fact that she is a social and friendly person; however, she has been isolating from others in recent years. For that purpose, she describes a scene in which she receives a phone call from a former colleague but does not answer it.

_Natalie: Well, I think they stopped ringing, I mean the phone would ring and I would just hear the phone and ignore it. So, people stopped after a while... but, you know, you are only friends when they say “oh, we are going out for drinks now why don’t you join us?” you just don’t feel like_

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1 All names are pseudonyms.
doing that... So, I didn’t feel part of that group because the job, the commonality had gone and I wasn’t involved in sports and get less and less involved in sports because... I took the artist route and the journalism route and the writing which is solitary... I cut off the groups, I cut off the ties.

Natalie’s narrative comes to explain the social changes in her life after being diagnosed with MS. This is a delicate task as she calculates the impact that MS has had on her identity, and at the same time designs a narrative that justifies her actions and leaves no question as to why she acted the way she did. In other words, her narrative revolves around agency.

The design of her narrative includes first the image of a ringing phone and moves on to another mental level that would now explain her actions: her belonging to this group of friends was established mainly on one intersectional identity that was related to her professional identity. Her next sentence implies the level of inclusiveness the group has, according to her subjective interpretation: “you know, you are only friends when they say ‘oh, we are going out for drinks now why don’t you join us?’” As mentioned earlier, there is no way to know how inclusive the group really was by relating only to Natalie’s text; however, the central point here is that Natalie did not interpret her relationship with the group as inclusive. Thereby she does not answer the phone. Her narrative then moves on to another aspect of her agency: taking “the artist route and the journalism route” meant, for her, choosing a path of solitude. Interestingly, it is not the MS that prevents her participating in sports activities, it is Natalie’s choice to focus on other areas of interest that lead to solitude. She is no longer interested in developing new relationships and reaffirming her self-identity as a friendly and social person. Instead, she cuts off ties.

Although she strives for agency that is constructed by negotiating her strangeness, Natalie’s narrative made me question whether this form of agency is an important aspect in belonging negotiation as well. If so, how does it impact social interactions? In addition, what forms of agency are available to people who experience a health disruption? And how does the change in people’s perception of their agency impact belonging and strangeness negotiation? These were all questions that developed and are later explored in the main research.

**Belonging**

Dimensions of strangeness led me to ask questions that are related to belonging: what would trigger individuals to choose to use their agency to establish belonging? And what would trigger strangeness negotiation? Natalie’s narrative was constructed around choosing to withdraw in order to manage her
strangeness; however, what conditions are required for belonging negotiation? Moreover, in what cases would a sense of strangeness lead to establishment of belonging to other individuals or groups? In other words, how does strangeness impact a sense of belonging?

Iris’s story helped to begin answering some of these questions. Iris, who was involved in a fatal car accident, described a situation that took place after her return from the hospital. She describes herself sitting in her car while being supported by her friend, Lilly:

*Iris: I was scared to drive again when I was out, I remember that, I remember Lilly, coming with me and sitting in the car just day after day, just getting me to imagine that I was going to drive the car again and I was crying and shaking and, healing, she just supported me to healing until the feeling wasn’t down and I could drive again, and I set that up because I had two little kids, I didn’t want to be scared driving.*

Iris’s narrative comes to reconcile a conflict in her identity: on the one hand she is a mother of two children, but on the other cannot drive a car and therefore cannot fully complete all her responsibilities as a mother, as she resided in a rural area and needed to be independently mobile. Her narrative, then, revolves around the notion of independence that is required for individuals to execute their social roles. After a fatal car accident, Iris was scared to drive her car: she describes a daily ritual (*day after day*) that involves sitting with a friend in her parked car. Returning to an object of fear that stands for loss of control triggers Iris with many emotions and she “was crying and shaking and, healing.” Even though the car is not a safe place in Iris’s mind, Lilly provided the safety that allowed her to break down and cry. She is crying and shaking, that is she loses control, but then she begins to heal and “*imagine that I was going to drive the car again,*” hence activating her agency. The car is not safe, but the conditions provided are. The event’s design is controllable as Iris is sitting in a car that does not move and she is accompanied by a person she trusts and can develop a sense of belonging with. The conditions allowed her to activate her agency and manage the implications of a health disruption while utilising belonging. These narratives assured me that questions around belonging and strangeness are relevant to the process of self-identity reconstruction, and the way their agency is executed after a health disruption. However, as will be discussed, I had to make a decision to return home and chose to examine these ideas further through conducting the main study in Israel.
Conducting the Main Study in Israel

All the above describes the original research design and the reason behind my decision to leave New Zealand after 2 years and go back to Israel. I felt exhausted after trying to overcome the challenges of my PhD, along with a difficult acculturation process in a new country. In March 2017, exactly 2 years after my arrival to New Zealand, I took a flight back to Israel. I was hoping to be in familiar surroundings and contemplate the process I had been through.

After a while, I rejuvenated and returned to my studies. I submitted a revised ethics application, which was approved by the University of Auckland’s ethics committee (Appendix D), to ensure that the research abides with both New Zealand and Israel laws and regulations that are related to research and privacy of participants, their dignity and rights.

Methodological Design

Significant methodological changes were made in the research at that stage: as mentioned before, the aspiration to portray participants’ life stories and incorporate secondary participants’ interviews was not successful during the pilot study. To simplify the context of data I decided to eliminate secondary participants from this research. I did not think at that time I was standing on solid theoretical ground in relation to secondary participants and their role in primary participants’ journey. Therefore, the main research study focuses only on primary participants’ narratives. The number of participants was expanded to eight; however, the principle of multiple interviews was kept. I was focusing on life-changing events and their impact on belonging and strangeness negotiation as interpreted by individuals who experienced health disruption.

Theoretical Development

The research pilot proved to be valuable in terms of understanding the conceptual needs of people during transitions and how that might impact self-identity construction. Stake (1995) claims that “there is no particular moment when data collection begins” (p. 49) since data collection can lead to some fundamental changes in the research process and the questions that shaped it (Yazan, 2015). The research pilot focused on notions of belonging and strangeness during biographical disruption and I aimed to locate other factors that could impact them, as reflected by the participants’ narratives.

Therefore, a table of themes was produced in order extract clusters of central themes which capture most strongly the respondents’ concerns about health disruptions (J. A. Smith & Osborn, 2009). Among these themes were choice (or lack of choice), belonging and strangeness. During this process, I
addressed narratives that reflected belonging or strangeness and attempted to identify the motivation for participants’ agency after a disruptive event. Categorical aggregation (Stake, 1995) was utilised at a later stage of the research to unpack the experience of belonging negotiation after a health disruption. For that purpose, I used categories of belonging, strangeness, choice, control, safety (that was divided into trust and notions of home), intersectionality, self-value, and visibility. These categories reflected not only participants’ renegotiation of belonging and strangeness and their agency, but also the process of self-identity construction. The subsequent table arranges the theoretical foundations, primary themes of the pilot study, and the concepts that originated from these themes, subsequently evolving within the main body of research. The table illustrates the progression of inquiries regarding the formation of belonging and strangeness, which were subsequently refined into the pivotal concepts of safety, control, and choice. These concepts constituted the focal points examined throughout the course of negotiating belonging and strangeness. Furthermore, the table also serves to highlight the emergent categories that surfaced and were subsequently investigated, encompassing facets like home, trust, agency, and more.

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<th>Theoretical Anchors</th>
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<th>Emergent Conceptual Categories</th>
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<td>Control</td>
<td>Primary Control</td>
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<td>Strangeness</td>
<td>PILOT STUDY</td>
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The narratives were dissected by using two axes: the first axis, as mentioned before, was used to understand what conditions are required for negotiating strangeness and belonging. The second axis used to analyse narratives was an intersectional perspective that searched for intersectional identities mobilisation that were involved in self-identity construction. As participants’ narratives displayed notions of helplessness along with other events in which the activation of agency took place, questions about people’s choices after health disruptions appeared along with a further unpacking of the conditions that are required for belonging and strangeness negotiation. After cross-examining the
factors mentioned above, analytic understanding was generated. However, at that point no hypothesis about the relationships between the concepts was constructed (Ridder, 2007).

The first factor that was identified as impacting participants’ ability to manage a sense of strangeness that was at times imposed on them as a result of a health disruption was an enhanced sense of control. As mentioned before, biographical disruption is defined as an uncontrollable event; however, mobilising resources, for example, can stand for people’s aspiration and activation of agency that enables them to establish a sense of control (Bury, 1982).

In fact, a tentative theory (Ridder, 2007) suggests that when participants were at risk of becoming strangers, some of them activated their agency in the form of control. This was a crucial understanding of possible relationships between an uncontrollable event, such as biographical disruption, and people’s agency to promote a sense of control. This was the first thread of potential relationships that different variables form during self-identity construction. However, it was clear that further examination is required to understand the link between all categories, and the reasons these links are formed. In other words, the goal became to understand not only which factors may impact belonging negotiation but also to decipher the underlying theoretical reasons for why these relationships exist (Eisenhardt, 1989).

Safety, which was divided into spatial and social aspects, home and trust respectively, was another factor that impacted the discussed process. Contradictory evidence between control and safety suggested that the relationships between the two were complicated, and an emerging theory attempted to reconcile juxtaposed constructions of the two concepts in relation to belonging and strangeness negotiation (Eisenhardt, 1989).

Lastly, inspired by the affirmative model of disability, a notion of choice regarding people’s agency and construction of self-identity was examined: what choices do people make in regard to their navigation in social world, if they attempt to reconstruct their identity as it was before biographical disruption, that undermine a sense of belonging? Choice was related to the intersectional process of self-identity construction, a sense of safety and control. Assuming that individuals’ lives are extremely affected by a biographical disruption then it could be hypothesised that their self-identity construction is interrupted as well. Therefore, what scope of choice do people demonstrate when managing their performance and self-identity construction? People are active social actors that cope with health disruptions in many different ways. How, then, are choices constructed in the social world? What components would social actors choose to establish in order to negotiate their self-identity? Would they always choose to utilise a
sense of control to establish belonging? Would they choose to establish a sense of trust in case a sense of control is undermined? What intersectional identities would they choose to mobilise during belonging, strangeness and self-identity construction?

As will be discussed in Chapter 8, an instrumental analysis developed the CSC model that revolves around the conditions required for belonging and strangeness development, and focuses on the dynamic that is utilised for self-identity construction. Participants’ narratives suggested that if one (or more) of the CSC factors is undermined due to a health disruption, then strangeness may be constructed. The notion of choice and the concepts of control and safety began to intertwine as participants described feelings of loss of control as a result of reduction in available options after a disruptive event. In fact, this topic was repeatedly raised during the interviews as participants attempted to construct a sense of control after an uncontrollable event. In addition, their sense of safety was addressed; participants spoke of the spatial aspect of safety that was usually achieved by constructing a sense of “feeling at home,” along with trust that is the embodiment of safety in the social sphere.

Belonging

To illustrate this theoretical development and to begin to understand the complicated dynamic between intersectionality and belonging and strangeness negotiation, I suggest utilizing two narrative sections. Despite the fact that the participants will only be introduced in the next chapter, these two narrative examples would hopefully promote the understanding of the intention of this research – to better understand the different facets that belonging and strangeness negotiation involve. The first example of narrative is provided by Tom, an 89 years old composer who lost his eyesight in his 20’s. The belonging construction he describes is related to his late wife, Lenna, who also had a visual impairment and whom he met during rehabilitation.

Lenna didn’t have to explain how it was like to live without being able to see. She could hardly see anything and grew up in a blind children’s institute in Vienna, and I didn’t need an explanation about the new condition. I knew... but she helped me greatly. First of all, she knew how to teach me music, how to help me learn it by heart. Teach me musical pieces, how to play them... we had a full cooperation along the years. We were a very unique couple, because we were together 24/7 all 54 years of marriage. There weren’t any issues of “I’ve had enough!” and each go to their separate way or, maybe there was a little, I can’t say there weren’t any
problems at all. And perhaps sometimes she felt she didn’t reach her own potential, she merged in me too much I think... But we were really together and worked in piano tuning together, and she Braille typed the music I composed... and she taught me musical pieces that were not available in Braille, or there were but I was too lazy to learn, and we worked together...

Belonging, as Crowley (1999) argues, does not only deal with questions of membership or duties and rights, but is also about complicated emotions that membership evokes. Lenna and Tom’s marriage demonstrate exactly that: working and living together, their sense of belonging was very strong, however Tom states that there were problems at times, and perhaps Lenna did not fulfil her potential in the music field as a result of supporting Tom.

In addition, meeting Lenna in the rehabilitation centre and developing a romantic relationship with a member who experienced a similar health disruption raised the potential for Tom to develop belonging to a community of people with visual impairments. Such sense of belonging, as will be discussed further, enhances self-value and self-confidence, and can assist Tom with incorporating an intersectional identity that is related to health disruption into self-identity. However, this is not the only identity shared between Tom and Lenna, as music brought them together as well. In other words, similar social locations motivated the two to negotiate belonging. The picture that Tom portrays leads to further questions regarding belonging and intersectional identities (perhaps sometimes she felt she didn’t reach her own potential, she merged in me too much I think), such emotions can challenge construction of original belonging and development of strangeness. Thereby it should be asked: do social actors always, under all contexts, negotiate their original belongings in the same way? What happens when conflicting belonging collide in one’s self-identity? Do individuals always feel a sense of belonging to their original culture in the same way? Further narratives will address these questions later on this thesis, and particularly in Chapter 7.

Belonging revolves around social places which are constructed by identification, and that allows stability of the self and a sense of “being a part of” (Anthias, 2008). The stability of the self cannot be understood without addressing the process of constructing a sense of belonging. Belonging, as discussed in the previous chapter, is about individuals’ social locations, identifications and construction of collective and individual identities, but at the same time stems out of the way it is assessed and evaluated by social actors who construct it (Yuval-Davis, 2011a).
In this sense, it positions social actors as active and with a competent agency they can utilise for both belonging and self-identity construction. Of course, the ability to construct belonging is not in the hands of social actors only. Both social structures and other social actors can impact this process. In addition, not all circles of belonging are as important to individuals in the same way and to the same extent nor provoke similar emotions (Yuval-Davis, 2011a). Construction of belonging, as with any social phenomena, is dynamic and may shift according to external events and internal changes (Yuval-Davis, 2011a). The way belonging is negotiated impacts directly on the construction of one’s identifications, and thereby affects self-identity construction. However, belonging cannot be fully understood without relating to its binary concept, strangeness.

Strangeness

As mentioned before, people construct a sense of belonging to groups through identifications and emotional attachments that are designed through collective and individual narratives; and ethical and political values which are the ways these identifications are judged (Yuval-Davis, 2006). However, it should be noted that while individuals may develop a sense of identification with others based on aspects of social locations or particular experiences, this will not necessarily lead to development of a sense of belonging. Furthermore, at the same time that people construct belonging to one group, they also negotiate strangeness towards groups that are different to them. One of the ways to utilise strangeness construction is the reaffirmation of one’s belonging to those to whom one is not a stranger. In addition, it is possible to gain social and political power by defining groups or individuals as strangers.

Daniel, who was diagnosed with hydrocephalus, describes his experience of belonging and strangeness negotiation after a health disruption:

_I am not in contact with anyone who has a similar condition. I was never offered such a support, like a support group or something like that. Usually, people in my condition would go to cancer support groups, because the symptoms are similar... But I think a support group to me means a group that wallows in its grief... With all due respect, I really don’t care how other people deal with their situation. I care about me and how I deal with it. I ask myself the questions and answer them. And I try to be honest with myself, but let’s be honest - we all lie to ourselves. So that works....I guess..._

The first important information that emerges from this narrative is the fact that Daniel negotiates strangeness towards others who experience health disruptions. As there are few patients with a similar condition to his, Daniel was suggested to go to cancer support groups as part of illness management.
However, the different intersectionality of the diagnosis was a reason for him to not attend their support meetings. This situation problematizes his relationship with an intersectional identity that is related to his health disruption, and thereby the potential for belonging construction is interrupted. Daniel’s solution is simple: he supports himself and is not looking for belonging negotiation with others who have a similar condition. According to Daniel, he asks himself the questions and provides the answers. However, it is clear that such an arrangement can be questionable as it brings up ontological challenges: for example, what is true, if we all lie to ourselves, according to Daniel’s narrative? When no external other is present to validate or challenge their narratives, individuals can tell themselves any story, regardless of the actual facts. Indeed, the levels of human creativity may lead individuals to believe in narratives that do not have to have a substantial hold in reality, as will be discussed in Chapter 5. This brings up a paradox in Daniels’ management of illness in regards to self-identity construction. He is aware of his inability to provide honest answers, and acknowledges the problems that his behaviour leads to. However, by negotiating strangeness to other who experience health disruptions, Daniel sustains his political power and ensures it is not diminished because he is affiliated with a stigmatised group. He denies any belonging to others who are stigmatised, and sets the foundation of his self-value in other circles of belonging.

Yuval-Davis (2006) suggests the theoretical framework of “the politics of belonging” which reflects the cultural mechanisms that are triggered by power relations and eventually determine who belongs to the group of “us” and who to the “others.” This theory relates not only to the construction process of boundaries but also to the ways in which agents are able to challenge them. Yuval-Davis (2011b) suggests that when discussing the politics of belonging it would be useful to examine the ways in which symbolic meaning is exercised and perpetuates the current social order; for example, who belongs, and who is excluded and marked as “stranger”. According to her, Bourdieu and Foucault offer relevant insights regarding power relation mechanisms and applications. Foucault, for example, discusses the “disciplinary society” which is generated through impersonal procedures and aims to discipline individuals and a collective’s consciousness (Yuval-Davis, 2011b). This way, society exercises power and knowledge in order to marginalise all that do not comply with the “norm,” such as people who experience health disruptions. This process could lead stigmatised people, according to Goffman (1963), to accept an imposed “spoiled identity,” and develop shame as a key emotion in regard to their perception of their identity, as Daniel’s narrative’s implies.
Strangeness is an important component of the self-identity construction process, and especially if a sense of belonging or strangeness is negotiated with a stigmatised group, as in the case of individuals with significant acquired physical disabilities, as will be further discussed in Chapter 5.

**Ethics and Recruitment**

For the main study, I used third-party recruitment methods by contacting local Israeli organisations for people with physical disabilities, such as The Association of the Deaf in Israel,2 The associations for the blind in Tel Aviv3 and in Jerusalem,4 Access Israel associations that assist people with mobility disability5 and empower them,6 and more. Organisations received a detailed explanation about the purpose of the research and its methods. In all situations, these third parties were not privy to knowing who decided to participate (or not) in the study as all potential participants were advised in the PIS to contact me directly, in a similar way to the recruiting process during the pilot study in New Zealand.

I sent third parties an information sheet with the research summary and asked them to inform potential participants about the study so they could contact me directly to express an interest to participate in it (Appendix E). At that point I was able to engage with them directly, answer any questions they had and ask them to sign a consent form if they were interested in participating (Appendix F). All information sheets and consent forms were translated to Hebrew as all the participants were Hebrew speakers. Two participants whose health disruption was related to their ability to see were offered a PIS and consent form in Hebrew Braille language; however, according to them that was redundant, and they preferred the information to be read to them by a person they trust.

**Coercion and Informed Consent.** The same principles around coercion that were set within the pilot study were followed for this study as well. Through the process of third-party recruitment, it is acknowledged that there is a risk of people feeling coerced to participate. To address this issue, potential participants were first approached by a third party, and if they wanted to receive more information, they could contact the researcher by email. At that point, the researcher discussed the possibility of participating in (or withdrawing their participation from) the research. To ensure informed

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2 [https://www.deaf-israel.org.il/blank-cujn](https://www.deaf-israel.org.il/blank-cujn)
3 [http://www.blind-il.com/html5/?_id=14670&did=12619&G=14670](http://www.blind-il.com/html5/?_id=14670&did=12619&G=14670)
4 [http://www.4jerusalemblind.org/indexEn.php](http://www.4jerusalemblind.org/indexEn.php)
5 [https://www.aisrael.org/eng](https://www.aisrael.org/eng)
6 [http://etgarim.org.il/](http://etgarim.org.il/)
consent and further address any concerns about power relations, an initial meeting took place, and participants were informed that they could withdraw from the research at any point.

**Pseudonym.** Choosing a pseudonym for the participants was quite a challenge in itself: at first explorers’ names were considered as they could signal the journey that participants went through; however, these names already carry their own significance which may bias the reader’s judgement as most well-known world travellers are associated with colonialism and imperialism. In addition, I could not find enough famous women travellers who are household names. Later, the challenge was to find pseudonyms that do not hold particular local Israeli or New Zealand cultural values, but on the other hand are not universal enough to objectify the participants (I was even considering using colour names at one point!). Since the thesis is written in English, I decided to choose pseudonyms that would not provoke strangeness to English speaking readers, but at the same time these names should not be related only to the New Zealand context as most participants are in fact from Israel. Eventually, I decided to use pseudonyms that are common both in New Zealand and Israel.

**Interviews and Translation.** As the interviews were conducted in Hebrew, I had to address the possibility that I would produce a biased and subjective translation of the narratives which participants in Israel provided. In that case, I used a back translation to minimise personal bias of the translated narratives and hired the professional services of “Zikit,” an Israeli company, that provided additional editing and important inputs regarding my translation of the total 17 interviews with the eight participants in Israel.

**Summary**

This research is based on methodological design that focuses on extracting the meanings that social actors construct. This perception views social actors as autonomous and with an ability to choose and impact their immediate social environment. Clearly, not everyone has the same range of choices, and social structures obviously impact individuals’ choices and behaviours; however, people are responsible for (and therefore are allowed to choose) their agency during self-identity construction.

My personal experience and subjective constructions have impacted both the research questions and the methodological development; however, I still hope to present a general model that can assist with understanding identity construction processes that take place after a health disruption. As mentioned

7 https://www.zikit.org/en/
before, unpacking constructions of belonging and strangeness exposed CSC factors. Later I will suggest possible links between them; however, it should be assumed that further research would uncover more links that are there to be found.

This research began with my travelling to New Zealand in the aim of enriching my knowledge about the acculturation experience and belonging and strangeness negotiation. Ironically, the research was eventually conducted in Israel, my home country. However, the research pilot in New Zealand was necessary both in terms of my personal experience and the development of the research questions and core concepts. Thanks to this journey I have learnt to appreciate familiarity and cultural knowledge and gained valuable knowledge about my social skills. Coming back to Israel enabled me to conduct the research in a supportive atmosphere, where I was able to reconstruct a sense of belonging. This would have not been possible without the help of the staff at the University of Auckland and my supervisors who have been very supportive of my personal situation. Without their approval to go back to Israel I would have not been able to complete my research and for that I am very grateful. My personal journey during the PhD enriched not only my research but also my perspective on life. The three main concepts that emerged out of the participants’ narratives echo my own journey.
Participants:

David
Aged 48, David has been married for almost 30 years, and has three children. He holds a PhD in psychology and works as an equine therapist at his own ranch. He was born in the UK and came to Israel when he was 18, to join the Israeli Defence Force. David worked in education and wrote educational programmes that were meant to express the Israeli and Palestinian narratives side by side. He was injured during his military service and since then has dealt with multiple injuries, including a broken spinal cord. He was also diagnosed with posttraumatic stress disorder (PTSD) and fibromyalgia which he continues to deal with. Today he dedicates much of his time to helping soldiers with PTSD, families of terror victims, and women who suffer from fibromyalgia. The interview took place over the phone and revolved around the injury and rehabilitation, his work as a therapist and the changes he went through.

Ben
Aged 46, Ben is single after two divorces and four children. He worked almost all his life in the defence industry of Israel but had to retire several years ago due to his MS. He was first diagnosed with MS at age 16 but was not aware of this diagnosis as his parents hid it from him. The first time he was informed he is diagnosed with MS was at the age of 28. The interview took place in his parents’ home (due to MS he is living with his parents). The interviews revolved around his relationships with his family, his former workplace, his previous hobbies—motorcycles—his caregiver, and his social circles (“able-bodied” people and people with MS).

Tom
Aged 89, Tom has been widowed for 10 years after 58 years of marriage. He was born in Austria and arrived in Israel with his family when he was 5 years old. Tom was injured in the Israeli–Arab war in 1948 and lost his eyesight. After the injury he got married, achieved higher education in music (and later became a composer), and worked for many years as a piano tuner. The interviews took place in his home and revolved around his growing-up years, the injury and rehabilitation, his relationship with his wife and her incredible support of him along the years.

Maya
Aged 89, Maya was born with eye problems that were not diagnosed until she was much older. Twenty years ago, she had a retinal detachment and since then is almost completely blind. Maya uses a cane but
tries her best to keep her independence. She worked most of her life as a special education teacher and music teacher. Maya is married with two children, one of whom died of cancer a year ago. The interviews took place in her home and revolved around her childhood and the challenges she coped with, her disappointment about not being able to get a driver’s licence, her family’s attitude towards her impairment, and her own feeling and coping with her condition.

Ella
Aged 29, Ella is single. At 16 she was hospitalised for a year to treat anorexia and was diagnosed with arthritis at 26. Arthritis has deformed her hands and is challenging her use of them. She is currently studying for her Master of Fine Arts in Israel and recently went abroad for an art internship. The interviews took place in her studio and later at her apartment, and revolved around her eating disorders, her art, the way she relates to her body, her relationship with her family, anxieties, and social performance strategies.

Daniel
Aged 39, Daniel is single. He was diagnosed with hydrocephalus 6 years ago. He lived in Germany as a child and returned there in his 20s, while he was working at the Israeli embassy in Munich. After returning to Israel from Munich he studied law and practises it still. Daniel came out of the closet to his mother when he was 23 but embraced his gay identity years before that. The interviews took place in his apartment and revolved around the diagnosis and treatments, professional identity, his relationship with his mother, social relationships and lack of intimacy because of hydrocephalus, and his life in Germany.

Sharon
Aged 48, Sharon is a mother of two. She has lived in Israel for her whole life, except for 2 years in New-York with her ex-husband and her children, before the divorce. She was diagnosed with MS 7 years ago. She used to work as a branch manager in a big retail company. However, in recent years she is not working due to her illness. Her father passed away 2 years ago. The interviews revolved around her strong relationships with her family, her divorce and dating new men. In addition, they related to her appearance and visibility of MS while managing issues of stigma and addressing issues of self-value.

Adam
Aged 43, Adam is married for the second time. His wife was pregnant with their first baby when the interviews took place. A few years back, because of medical complications that resulted from a simple
kidney stone removal, he was hospitalised several times and spent 6 months on sick leave. He used to have his own business for metal products repair but lost it due to the absence that his medical condition caused, plus a business associate who has proven himself to be unreliable. Not only he lost his business but also divorced his wife due to his medical condition. Today he is employed in a different company as a project manager and married for the second time. The interview revolved around the challenges he had to face after getting a divorce and losing his business due to his medical condition. His growing up as a “troublemaker” and negotiation of strangeness and belonging then and later were also a main part of the interview.
Chapter 5: Control

Introduction

This chapter discusses the importance of control and the sense of it in the lives of people with an unexpected health disruption. Stressful transition was a prominent feature in the narratives of most of the participants in this research as biographical disruption that resulted from a health disruption directly impacted their constructions of understandings of events. As such, they had to cope with notions of uncontrollability both in bodily and social aspects, such as coping with stigma. The first part of this chapter explores how the undermining of a sense of control can set the grounds for the establishment of secondary control (Rothbaum et al., 1982) by the participants. While primary control, as mentioned in Chapter 2, refers to behaviour that aims to directly alter the environment or other social actors, secondary control refers to what could be (wrongfully) considered as a “passive behaviour,” but is in fact utilisation of secondary means for constructing a sense of perceived control (Rothbaum et al., 1982). The participants in this research experienced an initial undermined sense of control as a result of a health disruption as they were not able to activate primary control and prevent its implications. However, they were able to utilise their agency to construct secondary control that assisted them to cope with the challenges that a disruptive event caused. Therefore, the first part of the chapter will unpack the different types of secondary control and their impact on participants’ self-identity construction.

The second part of the chapter offers critique of the medical model of disability, that is one of the three models of disability (along the social and affirmative models, discussed in Chapter 2), which seeks to fix the individual who does not fit normative definitions of what constitutes a “normal body” (Haegel & Hodge, 2016). Participants’ narratives demonstrated not only how the medical model impacted their negotiation of belonging and strangeness, but also how stigmatisation that is rooted in the view of the medical model of disability has impacted their construction of a sense of control. The undermining of their sense of control in this sense directly impacted participants’ self-identity construction and their belonging and strangeness negotiation; however, as mentioned, they were able to react and utilise their agency when coping with such process and reconstruct a sense of control. The concept of a sense of control, as mentioned in the previous chapter, was developed during the pilot study in which participants related to their lack of choice and ability to control their life course after a health disruption.
Control is only one aspect that I explore in this thesis, along with safety and choice—concepts I pursue in depth in the following next two chapters. Interestingly, the relationship between the three terms is sometimes overlapping: Averill’s (1973) three-fold typology of control suggested, for example, differentiation of behavioural control, cognitive and decisional control. Behavioural control is defined as the availability to execute a response that may directly influence or modify an event; cognitive control refers to the processing of an event in such a way that is meant to reduce a long-term stress or psychic costs of adaptation (Averill’s, 1973); and decisional control is defined as the opportunity to choose among various courses of action (Thompson, 1981). Hence, choice is not a separate from control, and in fact is utilised to establish a sense of control. The same goes for safety: home, that is associated with sense of familiarity and safety, is defined by Mary Douglas (1991) as a concept that “starts by bringing some space under control” (p. 289). This idea begins to explain why a sense of control is a key to thriving across people’s life span (Peterson & Stunkard, 1989).

Control can be defined as “the belief that one has at one’s disposal a response that can influence their aversiveness of an event” (Thompson, 1981, p. 89). Others define it as “the ability to alter events and achieve desired outcomes” (Greenaway et al., 2015, p. 3). However, the more this research progressed the more I asked what does it mean to influence an event? And what kind of desires might people seek to satisfy in uncontrollable events? How does it all influence a sense of belonging and strangeness? And how does it impact self-identity construction? A sudden change—made voluntarily or not—will cause shifts in outside reality and inside one’s personal world, as change itself can create confusion and interrupt a sense of control. Having been inspired by the pilot study to set a frame of control, these ideas were explored and tested amongst the Israeli participants in the research, assuming that there is a universal human need for the reestablishment of a sense of control after disruptive events.

**Pain and Stress**

According to Monat and Lazarus (1991), pain and stress are the two main reasons for people to require reestablishment of a sense of control. They define stress as “any event in which environmental demands, internal demands, or both, tax or exceed the adaptive resources of an individual” (p. 3). This situation can be experienced by individuals who experience a health disruption and can be harmful to one’s well-being and lead to further pain and suffer. One of the provocations of these emotions could be, according to Parkes (1971), an experience of loss: when people lose the support of their social networks or encounter a threat to their mental schemas that may also lead to a crisis which involves a
bereavement process. They may lose the ability to walk or see and will be limited in their ability to reconstruct their self-identity as it was constructed before. In fact, everybody may experience a loss that should be grieved upon during their lives (Parkes, 1971). Experiencing loss and the undermining of a sense of control is a universal condition: we all experience events that are outside our primary control, and therefore we all find strategies for exerting secondary control. This study merely highlights these processes in the lives of people who have experienced a particular form of loss of primary control related to a health disruption. However, the implications of this process can be relevant for any person that experiences a drastic life change.

The variety of feelings involved in the process of change and adaptation is highly influenced by the context of cultural contact; once again, the greater the cultural difference between a person and the new culture (as could happen in the case of culture of disability), the more they will have to give up on (Akhtar, 1995). The loss people experience can be related to external objects and relationships, as well as to internal aspects that are related to one’s self-identity (Smart & Smart, 1995). As self-identity cannot be reconstructed as before, the levels of stress may rise and affect the level of motivation to cope with life changes (Smart & Smart, 1995). Therefore, reconstructing a sense of control can help individuals to cope with the challenges that biographical disruption summon. The participants experienced physical and psychological pain that at times undermined their sense of control and led to increased levels of stress; however, simultaneously, they designed their agency around activation of secondary control that comes to dismantle, as much as possible, biographical disruption implications.

Part 1: Establishing Secondary Control
As established in Chapter 2, biographical disruption fundamentally undermines people’s sense of control, as they encounter the fact that this sense, which has largely been perceived as stable, can be significantly destabilised and ephemeral. When an uncontrollable event takes place people may attempt to change their external environment to fit their self-identity, hence activating primary control (Rothbaum et al., 1982). If this action fails, many would be inclined to activate secondary control, which is associated with changing themselves instead of the world (Rothbaum et al., 1982). Moreover, after a major unexpected event, people can begin to doubt the ability of their agency to execute primary control, and secondary control practices could take place.

Biographical disruption may lead an individual to develop a sense of secondary control in different ways, among them are acceptance, solitude, or construction of belonging, as the participants in this study
have demonstrated in their narratives. For some of them, successfully negotiating their belonging was the key element in the process of constructing a renewed sense of control, while others preferred to withdraw and rely on solitude for the same purpose. Both attitudes, however, reflected a deeper conflict between the participants’ need to activate social agency and the fact that life circumstances have uncontrollably and dramatically changed.

Instead of resisting uncontrollable changes, as primary control offers, and potentially experience success alongside failures in doing so, secondary control suggests an adjustment to situations and a safer journey for social actors (Rothbaum et al., 1982) as it is less dependent on external factors in people’s lives. However, the distinction and boundaries between primary and secondary control are not clearly defined as many situations involve both (Rothbaum et al., 1982). This is particularly true for the coping process that is linked to biographical disruption as “persons shift between phases of encounter and retreat in coping with a physical disability” (Rothbaum et al., 1982, p. 8) as they ascribe to reach an optimal coordination between the two.

Rothbaum et al. (1982) discuss four types of secondary control that can assist people to acquire a sense of perceived control. The different types of secondary control are:

- **Predictive control**—related to the ability to predict future events and plan accordingly.
- **Illusory control**—related to external locus of control, such as luck or fate.
- **Vicarious control**—association of self-identity with other powerful social actors.
- **Interpretive control**—the cognitive process that triggers construction of linearity of events, as well as their meaning and their impact on self-identity construction.

For a further understanding of the topic, the next sections will unpack how these typologies relate to the lived experiences of the participants in this research.

**Predictive Control**

Predictive control refers to people’s sense of the ability to predict future events and plan one’s response accordingly (Rothbaum et al., 1982), which has relevance to people who experience a health disruption and have to rearrange their expectations of the future as a result of it. The basic assumption that future events can be predicted and planned is mostly taken for granted by individuals, until it is disrupted. In this sense it is similar to the notion of belonging that is “taken for granted, until it seems threatened” (Yuval-Davis, 2007, p. 11). Planning one’s future is not an indication of control, but only a mechanism to construct a sense of perceived control by utilising secondary control. As mentioned in Chapter 2, the
notion of different types of secondary control exists within mental structures and is thereby considered to be perceived. Thus, the suggestion that secondary control exists “only” within mental structures implies it does not actually exist. However, if social actors believe this type of control exists, and behave accordingly, and gain a sense of control as a result of secondary control construction, then clearly it is real. However, the definition of secondary control as perceived acknowledges the existence of another social actor, who focuses their gaze at the construction of secondary control, and is able to identify the arbitrary links that exist at times between a sense of control and secondary control; however, it is a perception that does not diminish the effect of secondary control on an individuals’ life.

The issue of illness diagnosis, for example, can trigger a sense of control, in which case primary control could be activated and involve treatment and possible healing. However, even in cases of chronic illness, such as MS (with which three of the participants in this research have been diagnosed), a diagnosis can be interpreted partly as a relief and allow individuals to establish some sense of control: after searching for means to explain physical symptoms, a diagnosis turns what was considered as mysterious into something knowable and nameable (Frank, 1995). A diagnosis is usually the first step in the medical process that attempts to restore a disabled body. It contributes to a construction of a sense of control as it is a defined and accepted term that relies on historical routes and is socially legitimate (Frank, 1995). It is also a necessary step for society to grant individuals legitimacy for their physical condition (DePoy & Gilson, 2004) and instead of being labelled as lazy, crazy or liars, they can be categorised according to the diagnosis provided (Frank, 1995).

Ella: The doctor gave me the prognosis, and my sister was there with me at the hospital. And she looked at me, she was shocked, and she began laughing. And I asked her, “why are you laughing?” She replied, "I laugh out of shame, because we didn’t believe you all these years.” So, I could blame them... I could also blame my parents for underestimating my pain.

Ella, who was diagnosed with arthritis in her 20s, details her sister’s response to the information provided by the doctor: she first looks at Ella, she is shocked, and then begins to laugh. In a short sentence Ella describes the process her sister went through—from realisation, to shock and shame. Ella’s family did not believe she had an “actual” physical problem, and only now her condition was legitimised. The rearrangement of the meaning of Ella’s condition brings change and acknowledgement of her challenges by her social surrounding as well as the medical institution. As such, the tables turn and she claims she could activate primary control as now she has the legitimacy to do to her family what
was done to her, as she could blame them now for inappropriate behaviour. Her diagnosis, then, did not only provide a renewed sense of control but had the potential to impact belonging and strangeness negotiation with her close family.

Another example was provided by Maya, who has visual impairment from childhood and shared a narrative that explains how it contributed to the process in which she was labelled as stubborn:

Maya: On a train ride from Tel Aviv to Haifa I saw sheep and said, “look at the goats,” but everyone told me they were sheep. And I insisted they were goats and since then they called me stubborn. And no one noticed I couldn’t see well.

Until she was diagnosed with vision impairment Maya was “stubborn” as she insisted on the definitions that her impairment assisted her to construct. Only after being diagnosed, was an explanation provided for this characteristic and a potential for redefinition of her identity emerged. These two examples demonstrate the social impact that diagnosis had on participants’ lives as it redefined the situation and provided the participants the social legitimacy they lacked due to their physical condition. In this sense, diagnosis can lead to a sense of control as it organises one’s perception of self-identity in regard to an illness, as well as dismantling a stigma that was attached to them by others.

Diagnosis provides prospects of treatment and predictions of the developments in one’s physical future and a much-needed legitimacy that can ease their social life. However, what happens when misdiagnosis takes place? Firstly, misdiagnosis demonstrate that human abilities are not perfect at all, and not everything can be controlled. In addition, such diagnosis would impact individuals’ sense of control; however, their journey could become more complicated, shifting from a sense of control that is established by diagnosis and coping with its disintegration once it is shown to be wrong, for example.

Having said that, a correct diagnosis of a terminal or untreatable illness can simultaneously undermine a sense of control. Therefore, how is a sense of control impacted if a deliberate misdiagnosis takes place? The next narrative suggests a possible answer:

Ben: In terms of my illness, I’m not the average patient.... I was diagnosed with MS when I was 16... And I didn’t know it was MS, my parents kept it from me since they didn’t know if a 16-year-old boy like me could handle it. Fortunately, all symptoms I’d suffered from at that time had disappeared, and you could say that 4 months later they all went away as if nothing ever happened. And until I was 28, I’d lived a normal life. Back at that time my parents told me I had
viral neuropathy in my nervous system. Now, I knew what viral was, and it didn’t sound so scary, so, when it was done, I just went back to my normal life.

Ben was not the only participant who mentioned issues of misdiagnosis. Tom, a senior, did not reveal to his late wife that she was diagnosed with a terminal illness, and explained that:

Tom: She was 80 when she got ill. I couldn’t tell her she had Alzheimer’s. I never told her, and later she was not... in this world.

These narratives demonstrate a deliberate misdiagnosis that is provided by relatives who do so to prevent undermining the patient’s well-being. Therefore, it should be asked how can a deliberate misdiagnosis assist individuals? A deliberate misdiagnosis can contribute, in some contexts, to individuals’ sense of control that is not simultaneously undermined as misdiagnosis does not involve an illness that cannot be cured. Both Ben and Tom’s narratives revolve around a deliberate misdiagnosis that is delivered as a result of an individuals’ age: Ben was only 16 when diagnosed with MS, while Tom’s wife was 80 when she was diagnosed with Alzheimer’s. In both cases, their age had an important impact in the decision to provide a different diagnosis or not provide any diagnosis at all. Tom’s wife’s story is even more complicated as her illness impacted cognitive processes, and there was no guarantee she would later remember that she was diagnosed with Alzheimer’s. In Ben’s case, a predictive control could have been established as the diagnosis provided did not involve MS, an incurable illness, and therefore expected future events did not involve the threat of such illness to self-identity construction. A deliberate misdiagnosis reduced his stress (it didn’t sound so scary) and allowed him to continue his life as usual for the next 12 years. Had he received the correct diagnosis at the age of 16 then his life and self-perception might have been different from that point on, as his ability to execute predictive control could have been undermined.

Predictive control offers a particular set of interpretations that revolve around self-identity positioning and construction in hypothesised future events. This makes it an effective secondary control as this kind of interpretation may dictate the execution of one’s agency. In this sense, as the above narratives suggest, predictive control exists within one person’s mental structure and does not have to be based on an objective truth. As such, predictive control has a complicated role in people’s lives: this form of control would impact a person’s agency in a way that would correlate with their predictions about the future. Thereby, predictive control may be deterministic in nature. For example, an individual may assume negative feedback from others and that would in fact impact their agency in a way that would
provoke such social development. Hence, if interactions with others are assumed to result in negative feedbacks then such construction of predictive control, if executed, can lead to the same consequences that were initially anticipated.

**Illusory Control**

Illusory control is the second type of secondary control offered by Rothbaum et al. (1982). This type of secondary control usually characterises people with an external locus of control as it is related to forces external to the individual, such as luck. More specifically, illusory control refers to chance, fate or luck, superstitious behaviour, rituals, religious practices etc. (Rothbaum et al., 1982). Such strategy offers people the opportunity to align themselves with an external force and thereby construct a sense of control in another arena that can impact and undermine a sense of control in other aspects of life, as the body, for example (Rothbaum et al., 1982). It is not claimed that such external factors do not exist outside people’s mental schemas, rather it is suggested that whether they are true or not is not relevant. In this sense, the main principle of secondary control remains as the grounds on which one can establish a sense of control: it does not have to be proved to be objectively true in order to effectively impact individuals’ sense of control.

*Ben: Every activity is like going to war, if I need to take a shower then I have to spend an hour instead of 10 or 20 minutes, and not because I take my time, but because I do things very slowly and sometimes I would do it on purpose so I won’t get hurt... I was counting when I was doing things, 1-2, 1-2-3. Many times, I divided my actions into parts, so I counted 1, ok, I didn’t count to remember but to remind myself how long every action took before and how long it’s going to take now, so I count 1—ok I finished the first stage, 2—ok, this is finished now and we have number 3 left, it’s counting out of frustration.*

Ben divides his actions into parts: the first part is one, second part is two and so on until he completes the whole task, whether it be showering, tying his shoelaces, getting dressed etc. He is counting “out of frustration” because his physical condition has degenerated and his ability to perform these tasks is reduced. To cope with the frustration that results from not being able to perform as before MS, he begins to count and sets a new order of things: counting should indicate how long simple actions took in the past and how long they take today. This gives him an indication of his condition that may bring further frustration if tasks take longer to perform, but at the same brings order and a precise indication of what his abilities are at a specific point in his life. This illusory ritual does not help Ben to control his
external environment but to construct a perceived sense of control by a ritual that is meant to help him with his perception of “going to war” with what is a chaotic and uncontrollable event. By describing the situation as such, Ben not only provides a view of his mental state, that results out of loss of sense of control, but also provides a justification for his construction of secondary control that is not effective as primary control in solving objective problems, but enhances order and structure within his mental state.

Individuals who rely on an illusory type of control may perform a passive approach and reserve their energy and emotional resources for events in which illusory control is utilisable (Rothbaum et al., 1982). Through different means, such as superstitious behaviour, rituals or compulsive acts, individuals can invest their energy in events that assist with constructing this form of secondary control. Ella, who has suffered from eating disorders since childhood and was hospitalised for a few years due to her condition, describes her agency in forming a sense of control. Ella’s eating disorder is an inseparable part of her medical history and was one of the reasons her arthritis diagnosis was not provided sooner. Daily anchors and food rituals that Ella constructed have helped her to establish a sense of control that is related to her eating disorders and therefore can be assumed to impact other aspects of her body as well.

Ella: I have a food ritual. I eat every day for 4 hours. It’s my meal time and it takes place during specific hours, and I eat the same food, and during this time I get my sense of freedom. So, I have my daily anchors, my weekly anchors, but I don’t have any anchors beyond that. Every Friday I give space to my anorexia and my bulimia. I eat and vomit every Friday. It’s all very regulated and controlled.

One of the strategies Ella finds to reconcile the loss of control that her medical state led to was choosing an illusory secondary control: her food rituals provide a safe routine and a regulated sphere for her to construct a sense of control. However, Ella’s story is quite remarkable as it demonstrates how individuals can construct a sense of control by choosing an activity (primary control) that is destructive (I eat and vomit every Friday). In fact, she manages her eating and vomiting rituals by using the same cognitive tools. Despite that, a constructive interpretation provides her a sense of control as she is able to draw a clear boundary between herself and her disorders, and does so by managing them within a structured framework of fixed days and hours. Her narrative allows her to construct these boundaries that separate herself from illness (Bury, 1982) and thus an effect of perceived control is achieved, as she
constructs a relationship with her disorders in which she manages them, rather than being managed by her disorders.

A further development of this pattern of behaviour can relate to the intersectional process, in case one intersectional identity becomes salient during biographical disruption. Later it will be claimed that narrowing one’s identity to one’s physical symptoms will objectify them and may harm a sense of control. In this respect, the following narrative demonstrates a similar process that is utilised to gain a sense of control:

Daniel: I think I became more of a workaholic as a result of the illness. This happened because I had to prove to myself that I could still function on the same level as I did as beforehand. With the same level of sophistication, the same level of wit, with the same level of retrieval, the same level of intellectual capacity as I had before. And the same goes for my workload. My ability not to give up or disappoint. I know there are real things that have to be changed, when I can’t work, I can’t work. But for the rest, I had to prove to myself that I could still do it. Do you know how many times I burnt myself out because of this? Because I took on too much, or started working too soon.

Daniel constructs a sense of control and self-esteem based on his professional identity. His performance in the professional field after being diagnosed with a chronic illness (hydrocephalus) should reassure him that his condition is under control and cannot take over his entire self-identity. This is how he reaffirms his “ability not to give up or disappoint” others; however, this strategy can be dangerous as a too-heavy workload damaged his health in the past. He describes himself as a workaholic, which suggests a similar context to the illusory control that Ella established in which perpetual ongoing acts are formed to activate a sense of control. However, both participants put their health at risk by taking this strategy of secondary control construction, and in fact demonstrate that during the quest of control, many times individuals may in fact lose a great deal of control.

Vicarious Control

The third type of secondary control offered by Rothbaum et al. (1982) is vicarious control. Again, the external locus of control is relevant as vicarious control is aimed towards powerful other social actors. As opposed to those who view submissive behaviour as an indication of uncontrollability, the researchers view vicarious control construction as an active behaviour that aims to establish a sense of control that is linked to the concept of “belonging”: in times when individuals do not perceive
themselves as able to affect the environment, they may be able to construct secondary control by associating themselves with powerful other individuals or groups (Rothbaum et al., 1982). The participants in this research demonstrated different types of vicarious control; among them is a sense of control that is achieved by recognition that is provided by others, as well as a sense of value. Hence, a sense of belonging that was constructed with family members, close friends, work peers and managers, military officers, teachers and other education providers, caregivers, drivers, Facebook group friends etc., was utilised, at times, to gain a sense of vicarious control.

A few examples of vicarious control are religious believers and sports fans who derive secondary control from god or their sports team, and children who assert “my daddy is stronger than your daddy” (Rothbaum et al., 1982, p. 20). This secondary type of control suggests that if someone’s favourite sports team wins then their sense of control can be enhanced; however, the main focus is on the practices that allow social actors to develop affiliation to powerful others in order to establish a sense of control. This secondary type of control emphasises the social power of togetherness and a sense of belonging, rather than social practices that aim to establish a sense of control as illusory control suggests.

Vicarious control is interested in the practices that form belonging and trigger a sense of secondary control, such as weekly visits to the local church or attending sports events. In the case that an external source of power is a group, rather than an individual person, then a sense of belonging that is linked to a particular collective identity should be constructed in order to establish a sense of vicarious control. This sort of sense of belonging is more complicated than belonging construction that takes place between two individuals, as it does not always require an immediate feedback from another social actor. Instead, it is developed within the mental schema and can be based on an objective social reality, but does not necessarily have to be. In this respect, this kind of secondary control does not necessarily reflect an “objective” belonging that would be reaffirmed during immediate interactions, but in fact can be imagined as Anderson’s (1983) “imagined communities” demonstrate: this form of social construction does not require an unmediated feedback from the group at which belonging construction is aimed, and is in fact imagined by members, most of whom have never met or heard of each other and “yet in the minds of each lives the image of their communion” (p. 49). Even though Anderson refers to a wider sense of belonging that is reaffirmed with national institutions, anthems, flags etc., it relies on a common principle of a large group of people who do not know each member and yet (under certain
Ella: At first you need to invent your own story, and then you become it. You tell yourself you were never ill, that you live in a good neighbourhood, that you’re very rich, you can tell yourself any kind of story. And I do that all the time. If I find stories I want to be part of, I insert myself in them. At first, I may feel like they’re unrelated to my life but then I start connecting with them. It’s like my choice to take dancing lessons in a posh area rather than where I live. That was a choice, to go to another area, with all the dancers and rich people. And I decided to go there because then I could tell myself that I was part of them. And now I really do believe it, that I have a place there.

The above quote corresponds with the notion of “imagined communities” but is taking a step further in regard to the notion of “imagined” as Ella is actively and knowingly utilising her agency to construct belonging to a group to which she is a stranger. The mental process comes to elevate her social and physical status, which are obstacles for vicarious control construction in this case. She constructs a narrative that she knows is false and imagined but which has an internal effect on her as if it were true. Her narrative reflects in this sense both illusory and vicarious control: although she derives her control from a sense of belonging, she also objectifies others and utilises them as external factors to establish a sense of control. It is a radical narrative in a sense, but nevertheless exposes one mechanism that people utilise to deflect any differences they may have with a group to which they would like to belong.

A sense of belonging to a group of people can lead to construction of a sense of belonging to powerful others, and as a result, establish a sense of vicarious control. However, as Ella demonstrates, there is not always a need for positive interaction with others to establish a sense of vicarious belonging. During our conversations she referred to Robert Musil (1953) who inspired her to develop her strategy to construct vicarious control by offering the notion of a “sense of possibility”:

But if there is such a thing as a sense of reality—and no one will doubt that it has its raison d’être—then there must also be something that one can call a sense of possibility. Anyone possessing it does not say, for instance: Here this or that has happened, will happen, must happen. He uses his imagination and says: Here such and such might, should or ought to happen. And if he is told that something is the way it is, then he thinks: Well, it could probably just as easily be some other way. So, the sense of possibility might be defined outright as the
capacity to think how everything could “just as easily” be, and to attach no more importance to what is than to what is not. It will be seen that the consequences of such a creative disposition may be remarkable, and unfortunately they not infrequently make the things that other people admire appear wrong and the things that other people prohibit permissible, or even make both appear a matter of indifference. (p. 12)

The clash between reality and its potential can be reconciled, according to Musil, if the potential could be expressed freely. This is an existential thought that highlights people’s ability to choose even under the most uncontrollable situations, as described by Frankl (1963). This notion provides a basic sense of control, as suggested earlier.

Interpretive Control

All previous types of control reviewed so far reflect interpretive processes that aim to establish a sense of control (Rothbaum et al., 1982). Control involves cognitive processes of constructing meaning of past and hypothetical events and their impact on self-identity (predictive) in regard to questions of self-identity construction and belonging negotiation towards other people (vicarious) and concepts (illusory). However, interpretive control particularly assists individuals in making sense of events and processing them (Rothbaum et al., 1982). This secondary control type has multiple effects on people’s perceived sense of control. First, acts of constructing an explanation provide understandings of a strange sequence of events that has led to an uncontrollable result (Rothbaum et al., 1982). Regardless of the quality of explanation, it has been argued that written or oral expression can be utilised to provide a sense of perceived control. Sartre (1943/1966) writes:

To exist was to have an official title somewhere on the infinite Tables of the Word; to write was to engrave new beings upon them or—and this was my most persistent illusion—to catch living things in the trap of phrases: if I combined words ingeniously, the object would get tangled up in the signs, I would have a hold on it. (p. 182)

Narration of experiences allows internal process to take place; it promotes defining objects and impressions that influence self-identity construction. It provides a tool for deciphering what is perceived as reality and the self, and can lead to a development of a sense of control. As mentioned before, the type of explanations people usually hold can involve fate, probability, chance, god etc. (Rothbaum et al., 1982). However, such incorporation of explanation into one’s life story (and as a result, self-identity) can also harm a sense of meaning and perceived control, as people have a basic need for a set of
assumptions about the world and self upon which they operate (Janoff-Bulman, 1989), as mentioned in Chapter 2. These assumptions are part of the schemas that can provide a sense of perceived control if one’s world does not change; however, people may feel their schemas are under threat after a life-changing event (Janoff-Bulman, 1989). At this point it should be reemphasized that Janoff-Bulman's focus centres on trauma and the consequences of shattered assumptions, this research highlights the potential of utilizing secondary control as a form of agency. It can be claimed that a threat to schemas may call for primary control activation; however, when not possible, as mentioned before, people will be inclined to choose secondary control such as interpretive control, that will promote acceptance of events or at least provide a coherent explanation for the way things happened and the way individuals’ agency could be activated. Therefore, if an individual can construct meaning to incorporate a health disruption and its implications to self-identity and reconcile between them, their sense of perceived control would be enhanced.

People have the freedom to choose different interpretations of an event; however, it should be noted that different interpretations of situations may determine if a form of primary or secondary control will be activated (Rothbaum et al, 1982). For example, people may decide to reject what is forbidden or not accessible (Rothbaum et al, 1982). Therefore, if they think they are not provided with access to civil society and are stigmatised by others, then they may withdraw from society and prevent potential construction of belonging with others. Having said that, even choosing to deny one’s own authentic desires should be considered, according to Rothbaum et al. (1982), as an act of establishing a form of secondary control. Studies of this type of control indicate that, as mentioned, instead of changing the world people may attempt at times to change themselves and their interpretations of it (Rothbaum et al, 1982). By doing so it seems that they are able to experience a sense of perceived primary control over the levels of stress experienced.

Daniel: But I did go to the gym a few times a week. This is a huge part of life, especially for us gay queens. Gay male culture really focuses on the “outside,” people tend to judge the book by its cover. So, the whole issue of self-image, my appearance and my look were very important to me. [But the illness] didn’t change my taste in men. The point is that today it’s in reverse. I feel as though no one would find me attractive, so I don’t even try to find anyone to date. It doesn’t matter who or what I want because this avoidance comes from a sense of rejection that makes you feel like you can’t expect anything from others. What are my chances in the first place? I
imagine the rejection, and as a defence mechanism, I avoid trying to meet new people. And this is how I still feel today.

Daniel constructs an interpretation that is directed at his appearance. He first justifies the importance of his appearance by his belonging to the gay community that “really focuses on the ‘outside.’” As mentioned, several years ago Daniel was diagnosed with hydrocephalus and since then his appearance has degenerated, according to him, and this affects his belonging negotiation as well as self-identity construction. To unpack his experience, it should be asked how his interpretation provides him with a sense of control.

Daniel’s interpretation aims to form a predictive control about future intimate interaction. This dictates his primary control as he actively avoids meeting new people in order to not be disappointed as “no one would find me attractive.” According to Rothbaum et al. (1982), people might sometimes reject success in order to avoid disappointment later on. Fear of disappointment, according to them, undermines two levels of control as one might be disappointed not only by their own performance of a task (primary control) but also the ability to predict the outcome of an event, hence their ability to form a sense of secondary control is undermined. Those who expect disappointment, as demonstrated by Daniel, tend to view themselves as passive and low in self-efficacy; however, it could be claimed that they are choosing a strategy of “preparing oneself for the worst” which is actually an active construction of pessimism as a means of secondary control. Daniel’s interpretation of reality in which no other individual may find him attractive leads to this exact result as he does not give anyone the opportunity to find him (attractive) at all.

Another aspect of interpretive control that impacts predictive control, and more specifically is a time-related narrative, is offered by Ella:

One of the things about arthritis is that pain is changeable. In the past, the pain came at night, insane amounts of pain, but when I woke up the next morning it would all go away. So, I went on as usual. Your body doesn’t change, there is no external indication of the pain. So you also feel less motivated to treat it. You wake up in the morning and—nothing. No pain. So, you move on with your life, you don’t bother with going to the doctor... At night, I would have excruciating pain, and then would wake up in the morning and everything would be fine, and I would wonder, did it really happen? At that time, I started to realise that night time was different.
Ella describes times of stress and pain as her arthritis caused terrible physical pain during the night. The disappearance of pain during daytime impacted Ella’s motivation to see a doctor about it, and in fact her interpretive control led to passivity and self-doubt about her reality perception. Her body did not change, and the pain did not have any external expression, thereby her interpretive control was undermined. As a result, she did not explore the cause of her pain and therefore was not diagnosed and treated for arthritis. Notion of control begins to form when she defines night as “a different time” in which daytime rules do not apply. Time framing seems to be a channel in which Ella can understand and control her experiences: as mentioned, she set specific a time for eating rituals to manage her eating disorders, and in the current narrative she classifies night as a different time than day in regard to her pain in order to establish a sense of secondary control.

The human understanding of time has formed it as a tool for establishing control. The perception of time and use of language are human creations, similar to the notion of perceived control; however, they are extremely meaningful to Ella’s belonging construction as these are the tools that she can utilise for deciphering herself in relation to her body and her social environment. Medical experts cannot validate her feelings and as a result her understanding of her experience is limited. The definition of time allows her to cope with the fact that her experience is not comprehended by others; in this sense, time indeed is “not the achievement of an isolated and lone subject, but... is the very relationship of the subject with the other” (Levinas, 1979). Framing a time of pain within the construction of night allows Ella to gain a sense of predictive control as categories of time impact her experience of pain, a phenomenon that was still mysterious to her and to others.

Tom: I didn’t expect it. I had other injuries as well, and for some reason I didn’t think I would not be able to see ever again. I was convinced for some reason it would be temporary. Which doesn’t make sense whatsoever. If a bomb explodes next to you then you might be worried you will never recover from that injury. I always say—by the time I understood that I will not be able to see again, I already got used to it. So, I went through this with no significant crisis.

Tom, who was injured during one of Israel’s many wars and as a result lost his eyesight, provides a narrative in which interpretive control is remarkably important. At the time of the interview, he wondered how that could happen, how he could interpret his condition as temporary even though a bomb exploded next to him. However, his narrative once again demonstrates that secondary control does not have to be based on objective truth, as the interpretation of his condition as temporary was
not based on any diagnosis. This could have been a defence mechanism for not coping with a health disruption when he was not well enough to do so; however, in any case, that practice provided a foundation for construction of secondary control. By doing so he reached a point in which “by the time I understood that I will not be able to see again, I already got used to it.” His interpretation, then, motivated him to construct a sense of perceived control. This may have been the reason Tom did not experience a severe crisis due to his health disruption, as he claimed during his interviews.

The different types of secondary control that have been reviewed so far demonstrate the need individuals have when experiencing a disruptive event. In the case of health disruption, many of the social challenges that involve lack of control are the result of norms and views that are affiliated with the medical model of disability. The medical model promotes hierarchical relationships between patients and medical experts, along the idea that physical disabilities and impairments should be “fixed,” and as such can undermine patients’ sense of control as will be discussed below. Becoming objectified and being perceived according to physical misfunctioning can reduce people’s sense of control about their body as well as their self-identity and social positioning. The following sections will unpack the medical model’s impact on social life and particularly on a sense of control that stigmatised individuals may experience, and will discuss the different utilisation of secondary control to cope with such challenges.

**Part 2: Negotiating the Medical Model of Disability**

For much of modern history, disability has been viewed as a problem that should be fixed (Lindemann et al., 2017) and in many respects it still is. Framed within the positivist and absolutist epistemology, the medical model of disability aims to attain normality by forming and applying protocols of treatment onto individuals with disabilities (Shyman, 2016). The model suggests a perspective in which individuals and medical phenomena are considered as deficit (Haegele & Hodge, 2016), thereby disability is a medical condition that ought to be cured (Gillespie-Sells & Campbell, 1991), or at least controlled, before its members can receive equal opportunities. At its core, the medical model of disability revolves around the dichotomous categories of “disabled” and “nondisabled” that construct clear borders of what is accepted in different social aspects, such as behavioural, intellectual, aesthetic, and more (Shyman, 2016). This promotes the model’s objective to determine which individuals should be required to receive (what is contextually considered as) treatment in order to amend the consequences of their disability as much as possible (Shyman, 2016). From this perspective, individuals with disability should
be treated by professional others in order to either rehabilitate the difficulties that are caused by the disability or cure them of a disabling condition in order to achieve a level of normality (Shyman, 2016).

Under the dichotomy of “disabled” and “nondisabled” lies a deeper social segregation between those who are considered to be normal and those who are not (Shyman, 2016): as a result, deviation of acceptable standards leads to disadvantageous social positioning that is not be altered until the deficiency is fixed and rehabilitated (Shyman, 2016). A social implication of this view is that people with disabilities are exempt from the obligations and responsibilities that most members of society are expected to hold (Donoghue, 2013) which suggests that others will gain power over them to make decisions for them (Wolfensberger, 2000). In contrast, to be nondisabled would mean to be healthy, autonomous, active, mobile and capable of being a contributing member of society.

As mentioned in Chapter 2, the model of disability, with its conceptual framework and analytical tools, can be employed as a versatile lens to understand and relate to various forms of health disruption beyond the scope of traditional disability itself. This is because the model of disability emphasizes a broader perspective that goes beyond the medical understanding of impairment and delves into the socio-cultural, environmental, and attitudinal factors that influence an individual’s experience and identity in the context of health challenges.

When applied to other forms of health disruption, such as chronic illnesses or injuries, the model of disability enables a nuanced examination of the interactions between the individual and their environment. It explores how societal attitudes, physical surroundings, and systemic structures can impact an individual’s sense of agency, control, safety, and belonging. This approach facilitates a holistic understanding of health disruptions, recognizing that the experience of any health challenge is not solely a medical matter but also deeply intertwined with social and psychological dimensions. Due to this rationale, an examination and analysis of the medical model will be conducted within the context of health disruptions. The normative view of the medical model suggests that in order to function as valuable members of society, individuals who experience health disruptions are expected to cooperate with the medical institution (Haegele and Hodge, 2016). They are objectified as they are defined through their physical state, whether it is their medical condition, disability or impairment (Burke, 2008). In fact, physical symptoms become their defining characteristic and their identity complexities are narrowed to a mere bodily malfunctioning (Frank, 1995). As such, interactions with others are impacted and can lead
to construction of strangeness (Haegele & Hodge, 2016). Furthermore, not cooperating with this process of objectification and instead resisting treatment protocols adds another label to individuals as they may be considered lazy, unmotivated or even troublemakers (Haegele & Hodge, 2016). According to the medical model view, until a deficient human body can be “fixed,” social institutions should not give individuals who experience health disruptions the same opportunities as those who are considered to be healthy; thereby individuals who undergo health disruptions must commit to the treatment process until they are cured of symptoms (Haegele & Hodge, 2016). If one cannot be cured of their medical problems, then they may become objects of pity that are in need of help (Haegele & Hodge, 2016). The medical view would, for example, encourage charity actions that would perpetuate the social disadvantages of people who experience health disruptions (Haegele & Hodge, 2016).

The medical model sets clear boundaries between individuals who require curing and those who execute the treatment, and that reinforces a hierarchical and potentially inequitable relationship between professionals and people which experience health disruptions (Shyman, 2016). The model and its discourse, in fact, were developed when doctors and scientists replaced religious leaders as the authority in society over the body’s health and healing (Haegele & Hodge, 2016). As the medical perspective is focused on a pathological orientation of thought that seeks to isolate a set of symptoms from the healthy body (Shyman, 2016), it is centred on the notion of diagnosis and categorisation of whose bodily condition should be treated according to which medical protocol (Shyman, 2016). Hence, the body is objectified and treated as a machine that needs to be repaired in order to restore its productivity to society, while symptoms of health disruption are treated as alien to the body itself. In this sense, some of the participants linked their physical abilities to social ones. That is, only if their physical condition could be improved, and they could function “as normal” in society, then they could overcome social challenges. Other participants, on the other hand, constructed other interpretations about their place in the social world, which did not necessarily rely on the medical worldview, as will be discussed later in this chapter.

Addressing the authority of knowledge leads to Foucault’s (1963) understanding of the cultural crisis of medicine. According to Foucault, medicine is dangerous not only because it does not incorporate the entire body and mind in its understanding of physical symptoms, but more importantly because it is constructed in the scientific field that is not equipped to resolve moral issues (Hamraie, 2015). A shift from religious thinking to enlightenment thinking in the classical age developed the scientificity around
health disruptions (Hamraie, 2015) and instead of turning to morality and punishment in relation to physical symptoms, the focus has now shifted to dysfunctionality and repair. Foucault’s thought revolves around power: both religious and medical authorities treat health disruptions in different ways, however both gain power by the way in which people who experience health disruptions are defined and treated (Hamraie, 2015). The medical model revolves around power that coerces “able-bodiedness” and objectifies both treatment receiver and provider. Power is exercised in the form of controlling and taking over objects or people, as the aim is fixing people’s behaviours, thinking, appearance etc. This ideology impacted greatly on some of the participants in this research who had to cooperate with medical procedures they were instructed to undergo, and submit themselves to the treatment of professional others. Others described events in which they were shamed by doctors for not treating themselves as they were expected to, while others were prevented from having treatment because of their age or body condition. As the participants had to cope with external views of them as “ought to be fixed,” they had to generate their agency in creative ways to construct a sense of secondary control, as the next narrative demonstrates:

Maya: The relatives I stayed with wanted me to see a doctor who injected something to your eyes, which was supposed to reduce your prescription. I went to the doctor, and the doctor said that if I didn’t trust him, I should contact Dr. Cohen and consult him. I went to see him, and he told me not to do it under any circumstances. So, my relatives let me be. My vision impairment wasn’t a problem for me, but my relatives thought it must bother me, but I was fine. I studied, I went straight to second undergrad year, I completed my B.Ed., I worked as a music teacher in schools and kindergartens. I was fine even though I couldn’t see well.

A common criticism of the medical model is that medical experts should not have power over the lives of people who experience health disruptions, despite the fact that they have authority over the issues of diagnosis, protocols of treatment, and research of illnesses (Haegele & Hodge, 2016). For that matter, the medical model claims that medical experts are in fact the only powerful agents that are involved in managing health disruptions.

Maya, who has had a vision impairment since childhood, constructs a narrative that revolves around this issue as her agency of control over her body is silenced throughout it. Firstly, Maya’s relatives suggest she should undergo an invasive procedure to fix her eyesight despite the fact that she had been managing her life successfully and independently. Secondly, the only authority that Maya and her
relatives follow is that of a medical expert. Maya’s fears are not taken into consideration during this event, and her choice is legitimised only after the doctor’s advice. Her relatives’ approach stands on the medical view of untreatable health disruption as a failure of modern medicine: a situation that would indefinitely decrease the quality of life and well-being of people who experience health disruptions. This view could be utilised as justification for coercing individuals into treatment protocols and labelling those who do not cooperate with it, as mentioned before. As such, people who experience health disruptions must cooperate and obey medical authorities as well as becoming candid about their deficits (Good & Good, 2000). Maya went to consult the doctor to avoid the potential of being labelled as obstinate, irrational, or careless about her body (Good & Good, 2000), and prevent construction of strangeness with her relatives. She negotiates her belonging, then, by putting her agency at risk and following the medical model that regards people with disabilities as incompetent to make decisions for themselves (Good & Good, 2000). In this regard Maya holds an external locus of control, as the foundation for a sense of perceived control is the doctor, a medical expert. As a result, it could be claimed that she incorporates the medical model into her view and her self-identity construction, despite the fact that she has proven to herself and her social environment that she is perfectly capable of completing academic degrees and working in the educational sector even with her impairment.

Internalising stigma, then, can risk belonging and strangeness negotiation and may even lead to an identity crisis. That is because stigma does not impact only belonging and strangeness negotiation, but also self-identity construction. The way individuals can perform their intersectional identities is directly affected by the power relations that are constructed with medical professionals, as mentioned before. Daniel provides a narrative that demonstrates this idea very well:

*The first point is the level of stupidity you reach when you are a patient at the hospital. I think I can say that in the “real” world I am not a stupid person. On the contrary. Some would even say I’m intelligent, and I don’t think of myself as a stupid person. I’m cognitively active, so to speak. I ask and analyse, and understand; but you when you get to the hospital you become a stone brick. You don’t understand what they are telling you, it’s like you become a hillbilly that meets technology for the first time in their life. It’s the same! They talk to you and you don’t understand, and they tell you “we need to do this and this medical procedure” and you’re like “Ok.” You function only at the very basic level, you become an organism, an amoeba, and it’s
amazing because the only time I ever felt like this was when I applied for a mortgage from the bank.

Daniel describes an interaction in which his knowledge and analytical skills could not be utilised. This could result, of course, from the level of stress he experiences when he is at the hospital. However, his description of the situation focuses on feelings of inferiority to the doctors that stands for a similar dynamic that an individual from a cultural periphery (hillbilly) may experience when encountering “technology for the first time in their life.” As the interview was conducted in Hebrew, The literal translation of Daniel’s words was Fortuna Cohen from Qiryat Gat, implying an old woman of North-African descent who lives in a remote town in the South of Israel, which indicates the local cultural margins to which he does not belong. However, Daniel’s experience at the hospital positions him in a similar social position, and his narrative becomes even more drastic later, as he dehumanises his self-identity by turning into “an organism, an amoeba.” It should be noted, however, that this description of self involves Daniel’s sense of humour that is a strategy for constructing secondary control, as will be elaborated in the last part of this chapter.

Daniel’s narrative also demonstrates that the use of each type of control may indicate an actor’s social positioning in different contexts; if an individual is the most powerful agent within an interaction then primary control is usually executed (Rothbaum et al., 1982). On the other hand, execution of secondary control indicates that more powerful social agents are acknowledged (Rothbaum et al., 1982). It can be assumed that behaviours that are associated with secondary control, such as passivity, withdrawal and submissiveness, reflect a later stage of reaction to a sense of loss of control in which individuals express anger and protest behaviours that are associated with primary control (Rothbaum et al., 1982). Having said that, Daniel operates a sense of secondary control by utilising the narrative he constructs: at the time of the interaction at the hospital Daniel feels deprived of social power; however, constructing a narrative in which he can laugh about the situation and reaffirm his abilities, skills and knowledge (I’m cognitively active) is another application of secondary control that helps him to better cope with uncontrollable events.

Stigma

Medical models of disability have a direct impact on people’s life experiences, as well as belonging and strangeness negotiation and self-identity construction, as mentioned before. The model’s view leads to objectification and stigmatisation of people who experience health disruptions and as a result
undermines a sense of control. For example, according to Wolfensberger (1998), such individuals are devalued, othered, rejected from civic life and at risk of becoming victims of violence. However, the medical model is not the only source for social stigmas, as other stigmatised groups may demonstrate; the key interest of this research, then, is to focus on the implications of stigma and unpack it in light of belonging, strangeness and self-identity construction.

In addition, from a general society perspective, stigmatisation that excludes groups and individuals from the opportunity to negotiate belonging with it has a number of functions, such as exploitation and domination of individuals and groups, maintaining social inequalities in order to reaffirm existing power structures, or enforcing social norms in the case of deviant behaviour (Bos et al., 2013). Toni Morrison (1987) claims that “definitions belon[g] to the definers [and] not the defined” (p. 225). By stigmatising people who undergo health disruptions, and viewing them as fearful, tragic and different, society rejects the notion of health disruptions as they reminds it that “it is impossible to control all life events” (Kutner, 2011, p. 560). It could be an existential anxiety that motivates people to respond to the threat of loss of physical abilities that are considered necessary for life satisfaction, by rejecting people and objects that may trigger it (Kutner, 2011). This process involves labelling and stigmatising people who experience different health disruptions.

Stigma has a drastic impact on self-identity construction when it is internalised by individuals (Bos et al., 2013). Goffman (1963) claims that “the stigmatised individual tends to hold the same beliefs about the identity that we do. [This might lead him] to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility” (p. 7). Moreover, self-stigma can result from people’s awareness of the stigma that is attached to their identity by others and the social devaluation that is imposed on them (Bos et al., 2013). Since individuals can experience the implications of stigma in contexts that are in fact unaffected by their physical condition (Kutner, 2011), they comprehend that stigma has a direct impact on all their intersectional identities. Hence, external processes of stigmatisation in multiple contexts (that are related to other aspects of identity that are not attached to health disruption) would be impacted both by society and stigmatised individuals.

It is not uncommon for people who experience health disruptions to report lower life satisfaction than people who do not undergo these experiences (Daley et al., 2018). One reason for that is that people who experience health disruptions can be stigmatised, which means their identity is related to social categories towards which others hold negative attitudes, stereotypes, and beliefs (Crocker & Major,
1989). Stigmatised groups, for example, receive disproportionately poor interpersonal, physical access or economic opportunities relatively to other members of society (Crocker & Major, 1989). In other cases, one type of stigma can lead to further labelling, as Maya’s narrative demonstrates:

*One time my friends went to tune one of my student’s piano. And I forgot to tell the mother [of the student] that they are blind, and they walked in and she thought they came to beg for money. It was horrible, she was so mad at me. “How could you not tell me?” I felt so bad.*

As part of snowball sampling, Maya referred me to Tom, a retired composer and a piano tuner who later agreed to participate in this research, and in fact she is talking about Tom and his wife in this narrative. He himself never mentioned this incident; however, when talking about the stigma that blindness involves, Maya remembered that story as she felt guilty for not dismantling a potential perception of people with blindness as homeless or poor (who came to *beg for money*). She did not prepare the student’s mother, whom her friend does not see, so a stigmatising view of people with blindness was not prevented. In another interview Maya said: “*sometimes people with blindness are treated as people with developmental disabilities.*”

*Tom: The term blind, until this very day, I prefer using the term “don’t see.” I’m a person who does not see. It is better than blind because the connotation of blind is “as good as dead” and all kinds of images of miserable people. It was always like this. Calling someone blind is usually meant as an insult.*

Maya and Tom’s visual impairment is evident to others and thereby, as Maya’s narrative suggests, they experience challenges that are common to other visibly stigmatised group members. In fact, it is possible to replace the term “blind” with any other contextually visible and stigmatised ethnic group, and the principle of stigma remains. This idea reaffirms the understanding that stigma may be constructed based on different ideologies and cultural ideas but its impact and the way it is being operated by social actors is similar in different contexts. The way the participants’ agency was utilised by them to manage a stigma that undermined their sense of control can contribute much to the understanding of similar processes that take place in other contexts.

Experiencing stigmatisation can be stressful for those who are discriminated against, in that perceived discrimination could even be related to increases in blood pressure (Chaudoir et al., 2013), for example. Discriminated-against group members are also more likely to experience negative affective states and utilise maladaptive coping strategies such as alcohol or drug use (Chaudoir et al., 2013). Over time,
ongoing exposure to stigma-related stressors can impact one’s physiological system as well as their mental well-being (Chaudoir et al., 2013). Stigma impacts negatively not only people who experience health disruptions, but also individuals who are part of their social network (Chaudoir et al., 2013). Stigma by association, which is a social devaluation that is transferred from a stigmatised person to people who are associated with them, can directly affect the composition of a stigmatised individual’s social networks (Chaudoir et al., 2013). As such, they may facilitate greater homogeneity and limit the number of nonstigmatised individuals within the social network (Chaudoir et al., 2013).

**Visibility of Health Disruptions**

An important factor in the discussion of stigma is the issue of visibility: individuals are occupied with their performance in relation to intersectional identities that may become stigmatised in different contexts (Valenta, 2010). Nonvisibility of that intersectionality might lead to “passing” strategies, for example, and remain “discreditable” as long as the stigma has not yet been revealed (Goffman, 1963). The question of visibility is relevant to individuals who experience health disruptions that could be nonvisible. It is in fact relevant to any stigmatised group that their stigma is visible or not by others.

Sharon, who was diagnosed with MS a few years ago, told me about managing stigma in relation to dating, which she began to do a little while before the interviews were conducted. At that time, Sharon had a limp in one leg and that occupied her thoughts during this process:

> And there’s dating as well. Would you like to hear about that?... On my first date with this guy, I didn’t tell him I was ill when we spoke on the phone, and then when he saw me, you know, I wasn’t walking so well, so he asked, “What, what happened to you?” And I said, “Nothing happened, I have MS.” He didn’t know anything about it at that point. And I told him, “Do you want me to leave?” — “No,” he said, “like... why would you say that, why would you want to leave?” So yes, that’s part of it as well. On the one hand I don’t want to hide the MS, but yes, I am MS. That’s what it is. Yes, it’s like this thing, the question of whether you want to share that over the phone. Today, after a few times I told people on the phone, I decided not to do it anymore. Why should I? They should get to know me first; they should see me first. You know, sometimes people see me and tell me I look better in real life than my photos, like, many times... I don’t know, it sounds vain, but that’s what people have really said... and they wouldn’t believe I was 48, it seemed unreal to them... so all these things made me think—well, they should get to know me first and then we’ll see.
Sharon’s dating story revolves around an issue of intersectional identity mobilisation, or performance and acknowledgement of her MS during encounters with potential partners. Her first date confronts her with a choice she has to make about mobilisation of her intersectionality and questions of visibility that are related to MS. According to Kwon (2015), being an “outsider-within,” can enable individuals to make “creative use of their marginality” (Collins, 1986, p. 14, in Kwon, 2015, p. 625) and thereby use their agency to establish desired levels of strangeness and belonging towards different communities and individuals.

Researches of passing regarding ethnicity, sexuality etc. demonstrate individuals’ resistance to structural barriers: by passing as part of a privileged group, individuals gain access that would have been otherwise forbidden (Kwon, 2015). As Sharon tries to avoid stigma that is related to her health disruption, because it positions her as inferior during dating situations, she decides not to mention her MS during the first interactions with potential partners, but wait as “they should get to know me first, they should see me first.” She does not wish to be narrowed into one intersectional identity that is MS; however, at the same time, incorporates it into self-identity when stating that “I am MS.” To do so, she recruits two characteristics that should “compensate” for her health disruption: her beauty and the fact that she looks younger than her age. This choice could indicate that her positioning is aligned with those who discriminate against her for her MS. In other words, she emulates “the language and manner of oppressor” (Kwon, 2015) in an attempt to protect herself from discrimination and construction of strangeness. Her agency is not exercised in attempting to resist the form of oppression but to gain control by utilising the rules she dictates: she will tell others about her MS and allow it to be mobilised at the right time and place of her choice.

Goffman (1963) suggests that there are two types of stigmatised individual: the discredited and the discreditable. The discredited have stigmas that are visible to others, thus they have to consider how to deal with being stigmatised by others (Kutner, 2011). Individuals with visible disabilities are among the discredited in this sense. Their visibility means they may encounter discrimination and paternalistic attitudes on an everyday basis. They could, for example, lose confidence in other people and, as part of stigma rejection, refuse any offer of assistance, whether it is required or not. The dilemma of whether to accept or reject such interaction is complicated as it can contribute to strangeness that a person who experience a health disruption would construct towards those who offer help because it involves rejection of negative stereotypes of dependence and passivity of people with disabilities (Kutner, 2011).
People with nonvisible stigmas, on the other hand, would be considered as discreditable, and have a choice about whether to divulge information about their stigmatised intersectionality (Kutner, 2011). In this respect, a question of safety, and most particularly trust, becomes relevant as exposing one’s stigmatised intersectional self-identity would mean aiming to construct belonging. Visibility impacts directly on belonging negotiation as people with nonvisible disabilities can not only choose whether to negotiate belonging with a stigmatised group but also manage the “gaze” of society on them, as Sharon’s narrative demonstrates. However, an act of concealment can contribute to the construction of strangeness towards a community of people with disabilities, for example, and prevent belonging negotiation that is available to people with visible disabilities (Kutner, 2011). This would impact people’s agency in regard to their ability to cope with a stigma they are labelled with, for instance, they will not form solidarity with stigmatised others as a mechanism of defence from stigmatisation (Kutner, 2011).

Sharon: Sometimes I think that when people couldn’t see anything it was for the better, but also not. It was not only a good thing, they can’t tell that something’s wrong and you feel normal, but on the other hand you have to bear this difficulty, like if you can’t get over an obstacle, and no one would help you. Or they won’t let you go ahead in the line and they won’t try to be considerate. They think you are normal, like everyone else, so why would they let you pass or get through the line quicker?

At earlier stages of her MS, the invisibility of Sharon’s health disruption prevented the environment from noticing it, and thereby prevented acknowledgement of her condition. This means that she was treated as a “normal” person who has no special needs, and was left to cope with difficulties without any assistance from others as they were not aware of her MS. As such, Sharon had to invest a great deal of energy not only to function “normally” in the public sphere but also to manage her interpretation of events to maintain a sense of control and not get frustrated or upset that she received no help even though she needed it. Her nonvisibility at that time led to an inner conflict as self-identity construction involved silencing a meaningful intersectional identity at times. However, the negative feelings that are involved in this process are related, as in Sharon’s story, to the fact that she conceals a stigmatised and nonvisible intersectional identity, and therefore cannot gain acknowledgement of this identity by other social actors.

Daniel, like Sharon, is coping with questions of visibility in regard to his health disruption. Earlier in this chapter he provided a narrative about his insecurities because hydrocephalus changed his appearance;
However, the illness is not visible in the sense of this discussion. As such, Daniel conceals a stigmatised and nonvisible intersectional identity, and therefore cannot gain acknowledgement of this identity by other social actors. As part of this process, he must cope with the loss of memory, which has degenerated due to his illness.

*But this was definitely the most difficult challenge for me during this whole process. Obviously, it’s annoying, but like everything else, you develop compensation mechanisms, and you make jokes about it, but obviously, in general, you feel like more of a loser. It’s not the kind of thing that kills you, you just have to develop a compensation mechanism. By the way, this is just like with physical disabilities, the body will develop some mechanism to compensate for organs that aren’t functioning. The body adapts. So, it’s the same in my case. You just have to find the right tools to deal with it.*

Daniel uses humour to cope and adapts to the limitations that his illness brought. He claims humour and jokes can be used as compensation mechanisms; however, they still do not resolve the fact that during interactions in which he cannot remember important information he feels like “a loser.” His interpretation of actions suggests an analogy to Daniel’s behavioural coping mechanism and bodily compensation mechanisms: just as humour can cover the fact that he does not remember the name of the person he is talking to, for example, so the body “*will develop some mechanism to compensate for organs that aren’t functioning.*” As mentioned in the narrative, however, it is an imperfect mechanism, as “*this was definitely the most difficult challenge.*” His interpretation of events and his agency (humour) were utilised by Daniel to gain a secondary control despite the fact that he cannot control his physical condition.

Individuals with a nonvisible health disruption, as Sharon and Daniel demonstrate, are coping with a sense of loss of control in a more complicated way as they have to invest energy in a cognitive process around the fact that others are not aware of their physical condition. As such, they can choose with whom to share this information, and in which context to do so; however, that may add stress to their experience when interacting with others. Nonvisible stigma is usually implicated with concerns about the fear of being discovered that can lead to significant psychological stress (Bos et al., 2013). As a result, people with nonvisible stigmas may invest more cognitive effort during social interactions to manage their intersectional identity (Chaudoir et al., 2013). The price of better starting conditions during social interactions comes at the expense of “greater cognitive detriments” (Chaudoir et al., 2013,
p. 80) as they may risk social isolation if the stigma is revealed. It should be mentioned, however, that in some contexts, individuals with a nonvisible health disruption would face less prejudice in general than those with a visible disruption, and that may impact positively on their competence during social interactions (Crocker & Major, 1989).

**Coping With Stigma**

Stigmatised people experience and respond to stigmatisation in different ways (Watson & Larson, 2006). Not all people who experience health disruptions suffer loss of self-esteem and sense of value (Watson & Larson, 2006). People’s agency in regards to stigma varies and ranges from depression and passivity, to empowerment and motivation, to rejecting stigmas (Watson & Larson, 2006). According to Crocker and Major (1989), there are several mechanisms that help to protect individuals’ self-identity from the negative impacts of stigma. For example, stigmatised group members may attribute negative feedback during unmediated interactions to prejudice of others towards them. This way they are able to separate their self-identity as a whole and their stigmatised intersectionality, and utilise this mental buffer to protect their self-esteem (Crocker & Major, 1989). This mechanism is useful as prejudice and discrimination are perceived as nonpersonal on the one hand, and on the other hand are plausible to explain negative outcomes of interactions (Crocker & Major, 1989).

*Sharon: There’s this person I like but as far as he knows me, well, I’m not healthy. So, he decided to move on. Maybe he didn’t like other things as well, I don’t know. I can’t tell. I got caught up with the MS, but I can’t really tell... but then he did say it’s problematic. He said it. So I assume, but maybe it’s something else... Maybe I just got obsessed with that, because the MS is what’s bothering me, that’s where my insecurity is.*

Sharon describes an interaction she had with a guy she dated; however, she was worried that he saw her through an MS lens only (as far as he knows me, well, I’m not healthy). She designs her narrative around an ambivalent interpretation of events: she first thinks it was the MS that was the reason they did not continue their relationship, but then she withdraws from this conclusion (maybe he didn’t like other things as well, I don’t know) only to portray again her self-doubts about the impact MS has on her life. At that point, however, it is revealed that he said it—that is, he said that MS was the reason he did not wish to meet Sharon again. From that point Sharon designs her agency by focusing on herself and the inner feelings she had about this dynamic (maybe I just got obsessed with that, because the MS is what’s bothering me, that’s where my insecurity is) and by doing so constructs her narrative around
herself, and thereby her agency, as things could be different and the change is up to her. This construction comes as a response to an uncontrollable rejection she experienced along with her MS, over which she also does not have complete control. As mentioned, her narrative construction indicates an ambivalent interpretation of events, and this may indicate an undermining of a perceived sense of control. Linking negative interaction outcomes to an internal state or personal skills should lower self-esteem, while attributing them to external causes, such as MS, would protect self-esteem and sense of value (Crocker & Major, 1989). However, this is a two-edged sword: if stigmatised individuals believe that others are being kind to them or evaluate their work positively out of sympathy for their physical condition or fear of appearing prejudiced, then positive outcomes would not enhance self-value construction, and self-esteem may even decrease (Crocker & Major, 1989).

Another self-protective mechanism is formed through in-group social comparisons; that is, instead of comparing the status of people who experience health disruptions with those who do not, a stigmatised individual may benefit from comparing themselves to stigmatised others (Crocker & Major, 1989), as comparing oneself with members of more advantaged members of society can be painful and potentially esteem lowering (Crocker & Major, 1989). People with nonvisible health disruptions would, once again, be less able to use this strategy, partly because identification of similarly stigmatised individuals could be more difficult as the disruption is nonvisible. In addition, association with stigmatised others can reveal their own stigma (Crocker & Major, 1989) and jeopardise both sense of control and belonging. Of course, this assertion becomes more intricate in instances of health disruptions, as an individual who has encountered a life unaffected by health issues can draw comparisons between their previous state of well-being and their current condition, as well as with individuals who haven’t experienced health disruptions. However, even in the case of health disruptions the suggested self-protective mechanism can be questioned:

*David:* Most people don’t dive or go jogging every day, so if I look at it from a normal perspective, I would say I’m super happy, and things are going very well, I need nothing else. If I think of the challenges and the aspirations I still have, I haven’t done even half of all the things I would like to do.

In this narrative David compares his physical condition with that of a person who do not experience a health disruption, and points to the sport activities he takes part in (despite or because of) his physical condition: on the one hand a health disruption should have prevented him from being able to be
physically active; however, this health disruption means that if he doesn’t exercise then his body cannot function well. Despite the fact that David is coping with many different physical difficulties, he “need[s] nothing else”: he makes sure to exercise on a daily basis and have many plans for the future. David constructs a predictive control that motivates him to maintain an active and healthy life (If I think of the challenges and the aspirations I still have); in addition, he is prepared to experience both successes and failures, as any person without disabilities may face their future. In doing so he constructs an empowering narrative as he can compare his life “even” with those who do not have disabilities.

**Medical and Social Model Coping Strategies.** There is a central dilemma that occupies people with disabilities in regard to their coping strategies with a stigma: one side of this dilemma revolves around the medical model that aims to fix the symptoms of health disruptions, while the other relies on the social model that aims for a social correction in regard to disability rights, as mentioned in Chapter 2. For example, in their research of parents of children who experience health disruptions, Manago et al. (2017) claim that these parents manage stigma on behalf of their child as well as associative stigma. As such, they can deflect stigma by utilising the medical model to create separation of self from the stigma while simultaneously maintaining interactional smoothness and reinforcing existing social norms (Manago et al., 2017). Another option would be to utilise the social model of disability and challenge social structures and individuals who are responsible for labelling them and their families, which can involve interpersonal confrontation or political activism that evokes social discomfort (Manago et al., 2017).

The first strategy of resistance that is based on the medical model lies within the individual level (Manago et al., 2017). In other words, it revolves around a change of cognitive or physical aspects of the self that is required for functioning in a discriminatory society (Manago et al., 2017). Contrary to this approach, stigma challenging and the social model of disability call for changes at the interpersonal and structural levels of society (Manago et al., 2017). Manago et al. (2017) discovered that some parents deflected stigmas that were associated with health disruptions through individual self-development and thereby invested in medical intervention in order to minimise the distance between their children’s performance and socially expected norms. Through the medical lens, parents emphasised the medical component of disability and took responsibility for helping their children to reach “more closely approximate normative standards” (p. 173). This strategy, however, was accompanied with empowerment and comportment of their child as they had to cope with different challenges during
social life (Manago et al., 2017). In addition, parents pushed back against particular definitions of health disruptions that the medical model suggests: for example, the children were not considered as an object that should be “fixed” through medical means, but as a subject who was actively participating in their own trajectory (Manago et al., 2017). Participants in this research, as mentioned before, mostly conducted an ambivalent relationship with a stigmatised intersectional identity as they did not choose that identity. Therefore, as mentioned before, some relied on the medical model that calls for physical revision of the self, or formed different attempts to conceal a stigmatised identity. However, different approaches for coping with a health disruption have been provided by the participants as well. David’s narrative demonstrates this claim:

*When you go to therapy you begin at a disadvantage. If I have a problem, I would go to a therapist to help me understand my problem, deal with it and resolve it. And that is a result of power relations or assumptions that the therapist is better than me, or has the skills or the knowledge... When I treat people with the help of animals then I use an approach... there is an animal that has rights just like us, but because they are, let’s call it a disadvantaged group then there is a key dynamic and we should help the animal doing things they can’t do. We have to care for them, they can’t provide for themselves, can’t clean after themselves, especially if we put them in cages, they can’t get their food by themselves, I mean the experience of the patient in such case is an experience of somewhat equality between the patient and the professional, and together we take care of the animal. Taking care of the animal changes the whole experience because the patient is taking care of someone else, who at the same time takes care of them.*

David, who works as an equine therapist, suggests that the patient–therapist relationship can be hierarchical by definition as the medical model suggests. Instead, he offers a model that undermines the power relations and by including an animal within the therapy process he offers a construction of a different interaction, in which the patient provides care for the animal, and is not only receiving care from the therapist. In such case, the therapist is not the only authority, as the patient, and indeed the animal, are heard and impact the treatment process. The power relations in such form of therapy, according to David, are more equal than the medical model suggests and that can positively impact on a sense of control of the patient.
This is a social view of therapy as it undermines social norms of power relations between professionals and patients and can lead, under certain circumstances, to political activism and purposeful deconstruction of behaviour and social norms. David first experienced equine therapy as a patient and describes it as a positive experience (I felt I was literally “back on the horse,” he said during his interview). The horse provided him with what could be interpreted as a vicarious or an illusionary sense of control, as an external factor provided David a regained sense of control and helped him to cope with a severe injury.

Another example of coping through the social model of disability is provided by Ella, who has arthritis that challenges her mobility, and deflects the stigma that she might be labelled with by utilising the social model and deconstructing the meaning of disability:

_I think disability is considered to be something that people need to break through. It’s not something to victimise yourself about, it’s something that needs to be overcome. It’s something that should make you examine your boundaries, the boundaries of your specific body, disability is subjective, individual, I see it as a shape. There are so many ways to look at it. I love the word “disability,” disabled, and etc. I love it because I don’t see it as impairment. On the contrary, I see it as the opposite of impairment. For example, in terms of mobility-related disabilities. People can walk. Even if they can’t walk, they walk. It all depends how you define walking, or moving from place to place. We can deconstruct it. People move from one place another. Some are unable to walk with their legs. But they can use their hands, or use wheels. They move. At the end of the day, people move... we all move._

Ella’s interpretation challenges the definition of disability and does so by using three strategies: she first claims that disability is something that people should “break through” and overcome. That is, she calls for an act that aims to produce primary control by undermining an accepted social term of disability as a negative attribute. Her call continues as she charges the term disability with positive attributes (“I love this word”) and furthermore dissolves the accepted meaning of this term. To her, disability is a subjective phenomenon that impacts each individual differently. This idea is further developed as she unpacks the concept of walking: if the meaning behind walking is moving from one place to another, then it could be claimed that everyone can be mobile in different ways that are all legitimate. Her interpretation of her body, disability and self are utilised to deconstruct stigmatised intersectional identity and by this to form a sense of control and value.
**Belonging and Stigma**

Even though the principal structure of groups may, under certain circumstances, undermine personal autonomy and control (Greenaway et al. 2015) it may be the painful experience of rejection that can motivate people to construct a sense of belonging. People are negatively affected by exclusion because their intrinsic need for belongingness is threatened (Jetten et al., 2006). A few reasons may be used to explain why group identifications, imagined or not, can have positive implications for psychological adjustment (Zhang et al., 2018). For example, it has been shown that group identification provides a sense of belonging, a sense of meaning and purpose, a sense of control and agency, and a source for self-affirmation that increases intrinsic motivation and persistence to cope with challenges (Zhang et al., 2018). As people derive feelings of belonging, they can experience themselves as personally more capable and in control of their lives (Greenway et al., 2015). Their sense of perceived control increases alongside a sense of belonging, and this has an effect not only on their motivation, but also their self-esteem (Greenway et al., 2015). In fact, self-esteem can be implicated in two ways: in the first, low self-esteem promotes group identification; and in the second, group identification enhances self-esteem (Greenway et al., 2015). Some of the participants in this research had, in some contexts, renegotiated their belonging to original social networks; however, all the participants also negotiated belonging to a stigmatised group, and some decided to construct strangeness towards it. It is expected that an individual with multiple belongings should have a higher life satisfaction, fewer depressive symptoms and less sense of loneliness (Zhang et al., 2018). Having said that, in other contexts constructing multiple belongings and dealing with different normative expectations can also be stressful and lead to an identity conflict (Zhang et al., 2018).

*Sharon: I think I might be the reason I feel stuck and not the MS, because I believe I can be in a better physical condition and then I’ll be able to meet someone who is better for me, and not just automatically try to be with someone, well I have a disability so I should be with someone who has a disability as well. And I wouldn’t like to do that. I still feel I am “normal,” and not someone who has a disability, so I would like to be with someone who is normal. Not someone with a disability.*

Sharon claims that she feels internally “normal” that is, without a disability. Hence, there is the separation that Bury (1982) suggested between self-identity and illness, which is, as mentioned before, a defence mechanism of the self. However, such separation leads Sharon to the assumption that she
should reconcile her inner feeling through another person (her partner) who should not have a physical disability. In this sense, Sharon aims to prevent her disability from defining her relationship; however, by eliminating potential partners because they have physical disability, she is doing exactly that.

The belonging she negotiates, then, is to a culture of people without disabilities which is the group she identifies as the one that holds a valued cultural capital over stigmatised others, such as people with disabilities. As MS interrupted the construction of Sharon’s self-identity, she is also motivated to construct it as uninterrupted as possible, and thus would negotiate her belonging with people who do not have disabilities. She does so by constructing secondary control (I believe I can be in a better physical condition) and rejects others’ (and perhaps her own as well) expectations of her to develop relationships with a partner who has a disability.

It is assumed that discrimination reduces individuals’ sense of control; however, a sense of belonging that can be achieved by other group identification can reduce the impact of discrimination (Daley et al., 2018). Moreover, constructing a sense of belonging to a stigmatised group would not necessarily negatively affect people’s well-being (Crocker & Major, 1989) and identifying with a stigmatised identity may in fact be protective at times against stigma (Aviram & Rosenfeld, 2002). For example, a sense of belonging sets the ground for people to receive advice and support not only about how to manage their health disruption, but also the stigma that is associated with it (Charlton, 2000). It facilitates individuals’ access to collective resources that can resist stigma and empower them when coping with potentially negative impacts of discriminatory interactions (Ablon, 2002).

Ben: I did speak to mothers of, and it’s always very sad… if, let’s say, I’m at the hospital and I meet mothers of children who had seizures and are now diagnosed with MS, and these mothers have tears in their eyes, or I see a teenager after a seizure and his mother, or whomever is with him, has tears in their eyes. So I get there and I try to tell them—take this with the right proportions, because this is the first seizure, and it may never happen again. Time can heal, and perhaps it will go away without any sign, and who knows if and when another seizure will happen. You can prepare for the... you know what? I wouldn’t prepare myself.

Ben’s help for mothers (or other relatives) of children who underwent their first MS seizure is to construct a predictive control that does not necessarily jeopardise their perception of self. This information could be very different with the information most would probably have about MS, and its impact lies within the possibility that the diagnosis may not have a negative impact on one’s course of
life. Relying on his personal experience of a deliberate misdiagnosis (as discussed earlier), Ben claims that in their position, he would not prepare himself for the implications of MS, as the preparation may lead to a sense of loss and undermine his predictive control, and thereby his well-being. Instead, he suggests acknowledging the MS but not letting it define the future. An optional predictive control that Ben offered to mothers of teenagers after an MS seizure would not have been effective if Ben had not constructed trust with these mothers, hence a potential for belonging emerged.

Having said that, a sense of belonging to a stigmatised group has its social cost during intersectional processes as it requires individuals to affiliate their identity to a devalued group, and thereby potentially stigmatise intersectional self-identities (Crabtree et al., 2010). This presents a dilemma, for example, to those whose health disruption is nonvisible and who are inclined to pass as people with no health disruptions. Although in some contexts, such as medical or welfare-related contexts, people with a nonvisible health disruption would actually prefer to disclose it, while in other contexts they would prefer to conceal their health disruption. Not only context determines whether people decide to perform their identity in a way that exposes their health disruption, but also the level of group identification. For some, a sense of belonging to a community of people who experience a similar health disruption is a central part of their self-identity construction and they feel a strong emotional connection to other group members; for others, a sense of belonging to a similar community would not be as important and they would instead prioritise their individual self over collective concerns (Spears et al., 1997). At any case, however, the combination of high discrimination and low levels of belonging has a large, negative effect on life satisfaction (Daley et al., 2018).

**Summary**

Control is a sense that is undermined when people experience health disruptions and that directly impacts their belonging and strangeness negotiation, as well as their self-identity construction. This process would be further impacted by basic schemas that are undermined during a health disruptions, which may lead to shattered assumptions. This would remodify the ability of individuals to execute primary control and would lead to development of strategies that are related to secondary control.

Once again, the definition of secondary control as perceived could be problematic from a social actor’s point of view, as secondary control can have a similar effect to primary control on individuals’ lives. However, as mentioned in Chapter 2, the term perceived refers to an external other that views secondary control from an outside, and a required, perspective, and is able to identify the illusionary
component that secondary control involves. A sense of control is a universal need, and all humans experience secondary control during their lives as a result of the fact that not all aspects of life can be employed by a primary control. As everyone finds themselves at times relying on a constructed secondary control, it would be accurate to say that in a sense we are all utilizing a perceived notion of control; however, that does not derogate the impact it can have on the individual that constructs it.

Secondary control does not aim to impact the external world directly, as primary control does, and this is where its advantage lies: secondary control is not dependent on external reality and at times is not even based on objective truth. That is the characteristic that makes it very useful in times of uncontrollable transitions: the meanings that individuals construct during and after health disruptions are designed to provide them, alongside other needs, with a sense of control. An optimal interpretation of events would not only provide coherence but will positively impact one’s self-identity construction.

This chapter has reviewed several strategies that were utilised by the participants to construct a sense of perceived control despite nonelected and uncontrollable drastic health disruptions; as well as to cope with the lack of control that the medical model of disability can cause, regardless of the reason for a drastic life event. Whether physical disabilities or chronic illnesses, the participants had to engage their agency to cope with the changes in their lives. By utilising external factors, behaviours and/or other social actors, the participants in the research proved it is possible to establish a sense of secondary control that is important when coping with life transitions.

Some of them had to cope with their predictive control being undermined as a result of a health disruption, as well as loss of expected future, and for that purpose constructed belonging with others; while others preferred to negotiate strangeness, withdrawal and protect themselves against potential disappointments. In addition, the participants were able to utilise secondary control for establishing control in aspects of their lives that were not directly linked to an intersectional identity that is related to a health disruption.

The participants were challenged not only by health disruptions, but also stigma that relied on the medical model; a process of stigmatisation undermined their sense of control and the narratives they provided reflected an ambivalence that was involved within self-identity construction, especially in cases of nonvisible health disruption. In this sense, the narratives demonstrated another important aspect of a sense of control that is the role of society that can either expropriate individuals of their control or grant them a sense of control. This means that the context, with all its implications, determines what form of
control will be constructed and what role society will have in regard to that construction. In the case of dealing with stigma that may mark a social actor as the other, the participants found different ways, related to both the medical model and the social model of disability, to cope with a stigmatised intersectional identity. They executed their agency effectively to validate their own interpretation of what health disruption is, and whether it restricts the body and/or the mind.

However, control is only one factor that impacts belonging and strangeness negotiation. Another crucial factor is the ability to construct a sense of safety, and more particularly trust, as will be discussed in the next chapter.
Chapter 6: Safety

Introduction

Safety is an etymologically problematic concept. I may have chosen this term due to my limited English vocabulary, but the word “safety” as I understood it seemed to surround a specific aspect of a sense that participants described and related to; at times as something that enabled them to develop belonging, while at times its absence led to strangeness. However, the term did not satisfy the variety of references that were provided by the participants. Safety, then, had to be divided into two concepts, “home” that is related to the spatial sphere of safety, and “trust” that is linked to the social sphere. Both trust and home are relevant terms for the discussion of belonging and strangeness negotiation after health disruptions: trust can sometimes function as a motivating factor for strangeness construction, for example, if individuals are perceived as trustworthy or not. If we accept the claim that belonging and strangeness are core motivators in designing self-identity construction process as forwarded in Chapter 3, then a sense of trust and home are central features in establishing a sense of safety to navigate health disruption.

This chapter explores the notion of both home and trust and how they are constructed after a health disruption. The notion of home brings together both people who experience health disruptions. They reconstruct their interpretations regarding new spaces that might stand for places of safety or not. The concept of home also reflects a basic feature of self-identity construction: as a physical sphere it can be designed by individuals to reflect their cultural belonging, and thereby sections of their self-identity.

Later, the chapter discusses questions that revolve around trust and how it can be constructed after a health disruption. Trust is a fundamental feature in belonging negotiation, and its absence impacts dramatically the way belonging and strangeness are negotiated. Lack of trust, for example, can trigger a primary or secondary sense of control. At other times, both trust and control are required for successful belonging negotiation. Trust and control, in fact, have a complicated relationships: trust could stand as the opposite of control, as trust is an expression of social actors’ agency and control stands for cultural structures. However, at times one cannot be executed without the other. These complicated links between trust and control have a direct effect on both belonging and strangeness negotiation, as well as self-identity construction, particularly after a health disruption takes place.
The ability to trust others and to be trusted is part of individuals’ agency to negotiate their belonging and impacts one’s self-identity construction during health disruption. Therefore, the participants in this research have been asked about the ways they interpret trust and how it was constructed in their lives before and after a health disruption. Assuming that a person who experience a health disruption could manage a stigmatised intersectional identity, how are notions of trust constructed after such disruption?

**Home and Agency**

Home is the spatial perspective of safety. It is related to a person’s ability to feel safe within a physical arena, and the impact of this sense of safety on social interactions that take place within that arena. The participants’ sense of feeling at home was an important theme for some of them, as their sense of safety was harmed during medical procedures in spaces that did not feel safe. Others had to move to another residence as a result of their health disruption, let care-providers into their homes or spend a period of time in rehabilitation centres. The importance of safety and a sense of feeling at home were discussed during the interviews, then, as an important aspect that impacted their belonging and strangeness negotiation.

The public sphere and home seem to be dichotomous concepts; however, even in public spaces there are different degrees of safety that can be interpreted, and thereby can represent higher or lower levels of feeling at home. For example, a study conducted by Wiersma (2008), who examines a sense of feeling home at a veteran’s hospital, examines the ways in which veterans with dementia make meaning of their environments, including the hospital and a summer camp in nature. She suggests a definition of home as a construction of memory, that is the notion of home as one that includes the social relations and life experiences, and freedom to act as desired (Wiersma, 2008). The residents of the hospital who considered home as the centre of social life were able to refer to the hospital as their home; however, for others, who may define home as a place of independence and freedom of action, then the institute’s restrictive nature and structured routine, along with its locked doors and the necessity of an escort when off the institute’s ground, would have prevented the option to construct a sense of feeling at home (Wiersma, 2008). For most the participants, Wiersma adds, the facility was perceived as a temporary place to which one does not develop attachment. When the participants in her research were given the opportunity to attend a summer camp in nature, they were able to construct a sense of home as the sheer participation was at their disposal. Rather than detaching themselves from the social context, as they had done in the hospital, the relative freedom of choice (to participate in the first place,
and in which activities to participate during the camp) allowed them to construct an attachment and a sense of belonging to the social surroundings (Wiersma, 2008). Such comparison raises the importance of choice in the process of construction of a sense of feeling at home.

An important aspect of public spheres in regard to the notion of home is the presence of other individuals. Whereas home represents safety and privacy, public usually stands for the opposite. This raises an important notion of the gaze of other social actors on the participants, and the issue of choice as a factor that impacts others’ gaze construction. In this respect we should turn to Ella’s experience in Tel Avivian cafes, which she has recently begun visiting and bringing her lap-top so she can do her work there:

> At first, I didn’t understand how people could do their work there, it’s so noisy, but then I realised that that noise was actually providing silence. It’s a lively noise, that doesn’t intimidate you and you also feel like you’re being observed. There are eyes on you as someone who’s working, like I... I remember telling a friend that sometimes you need a video camera to move, in order to do something, to be able to get work done, because there is an eye that’s watching you and can see that you’re actually doing what you’re supposed to do. You’re impressing someone’s eye. I know that when I go to cafes no one is actually watching me work, but it doesn’t matter to me, I can imagine that people are looking at me working, being busy. So, I utilise this impression, I have nothing else to do other than be busy.

This narrative reveals a fascinating notion: an observed performance, as “there are eyes on you as a person who’s working.” Ella suggests that the objectifying gaze of others on her in the café to help her stay focused in a productive activity. Of course, Ella has chosen to be viewed by others at the café. Perhaps this is a crucial difference between the objectifying relationships that are imposed on individuals, as Sartre (1943/1966) suggests in the term “the look” (p. 252) and the experience Ella is describing. She does not discover herself as an objectified subject, but utilises the process of an imagined objectification of herself into a performance of a productive object. In other words, she uses agency, her imagination, to uplift herself from a physical phenomenon (a look) and perform a pretended, wishful identity. She later adds that the look does not need to be generated by other people, but can be produced by cultural artefacts, such as a camera. By this she makes human involvement in her objectification process redundant and raises many questions about our social functionality in
technologically advanced society. In other words, her performance is based on a look, but it does not have to be a human look.

Performance is relevant to the issue of identities construction and the ability to “fit in” which elaborates a potential to construct a sense of belonging. Man, claims Victor Turner (1979), is “homo performans.” His performance is reflexive, as through this process “he reveals himself to himself” (p. 72). Turner suggests that the origins of the word “performance” are derived from Old French *parfournir*—*par* (“thoroughly”) plus *fournir* (“to furnish”), hence performance does not necessarily mean the actual manifestation of social form, but rather to “bring to completion” or “accomplish” (Turner, 1982). In other words, to perform is to complete a more complex process than to do a single act (Turner, 1982). External space can provide individuals with a sense of safety or insecurity, especially in the case of public spheres, and that would impact social actors’ performance. In this case, the fact that Ella chooses to participate in that space allows her to construct a satisfying performance that can impact her self-identity construction.

Performance is an important aspect of the construction of the self and can be presented through the performance of roles, and through performance that breaks roles (Turner, 1979). This definition is closely related to Goffman’s (1959) theory of self-presentation which demonstrates the various ways in which the self is presented and performed in different social interactions. The reflexivity which is involved in performance, as Turner (1979) suggests, can be achieved in two ways: The social actor may come to know themselves better thorough acting, or through observing and/or participating in performances generated and presented by other social actors. In fact, one’s ability to feel safe and in control within a spatial sphere impacts their performance: in some cases, the reflexivity which is evoked by performance constructs the mental boundaries between “us” and “them” (Turner, 1979).

Bell (1999), following Judith Butler, suggests that constructions of belonging have a performative dimension. According to Butler (1990), performance constructs identity, and not the other way around. Hence, we do not “naturally” belong to any group, not even a gender or sex group (Bell, 1999). In regard to construction of a sense of belonging, Bell (1999) suggests that in order to construct belonging there is a need for repetitive practices which relate to specific social and cultural spaces, and which are meant to connect individual and collective behaviour in order to establish an attachment (Yuval-Davis, 2006). As in other forms of performance, performativity of belonging reaffirms the norms and values that constitute a community (Bell, 1999). But what happens when public space does not feel safe? How
would that impact one’s performance and thereby one’s belonging and strangeness negotiation? The following narrative may provide one answer to this question:

Daniel: It takes 5 hours and you have to sit there alone. Alone in a room, after you were electroshocked, and you know it’s coming, but there is nothing you can do about it... And then you are like a dead man. Then you begin to vomit. Now, it’s not like they’re doing anything wrong. They’re fine, they do everything they can but... but... but you are alone. You are basically alone, and there is nothing you can do, not even crawl under your blanket, which is like... it’s very comforting, I don’t know how to say it, perhaps the fact that you can cocoon yourself, it’s very, very comforting. It’s like you are inside your own protected space. If I’m in my own small space and I’m... It doesn’t matter what the consequences will be, the consequences are always bad, but I’m inside, inside that bed within that frame, and I know I’m cuddled, and I feel... like... let’s call it invulnerable. I can rest there. But when you’re in public, everyone is watching you, you’re not in good condition, you don’t feel well, and you have to keep a facade, and this loneliness when you know you have to keep up this facade but you feel so terrible, it kills me. It kills me because you feel the muscles, how your strength leaves you and you cannot act in the way you are expected to in public.

It is quite easy to see why Daniel is going through a negative experience during his treatments for hydrocephalus: sent to isolation he has to remain there for a few hours and bear the fact that he can be watched by others, while his body evades his control. His lack of bodily control could be compensated if he had a “spatial frame,” such as blanket, that could be utilised as a protected space that allows, among other things, him to gain control over others’ gaze at him.

The difference between the gaze Ella speaks of and this one is rooted in the concept of choice: Ella chooses to enter a space in which she feels safe, while Daniel is undergoing a process which he had no choice but to go through, and hence has no choice during it as well. Therefore, the meaning provided to a similar gaze is different, and the potential for belonging/strangeness is established. In this case, Daniel’s performance of his identity is not as authentic as he feels (both physically and mentally). He refers to a “facade” he feels obligated to keep in front of others. This is his choice of how to manage the unchosen gaze of others; however, such process may lead to self-objectification, hence strangeness towards self. In an existential aspect, most people never perform their authentic self or follow their genuine desires before doing anything else for another person (Silverio, 2019); however, in this case, the
authentic self is deeply affected by hospital treatments and is repressed in a way that “kills” the speaker. It is a harmful repression of the effects of an experience, and additional cognitive process is required to reconcile its effect on self-identity construction under such extreme conditions.

Daniel: You could ask for things by the way. They will do it. But they won’t be proactive about it, or understand what a patient is going through mentally. I don’t blame them. And you know what? Perhaps it’s for the best, because it makes me stronger. I’m a bit of a “Soviet” in this respect, and believe in a person’s need and the ability to deal with things by themselves. And perhaps if you’re too cuddled and cared for, and everybody understands you and understands your needs, then it weakens you and your motivation to develop coping skills and deal with your circumstances. Again, some would say I’m wrong, but at the bottom line, if I would ask for something, they would give me what I needed. The problem is that when you get there, your condition doesn’t let you ask for anything.... You’re vomiting, you can’t speak, your leg is numb, your mind is foggy... and despite that, since I have gone through this quite a few times now, in some way I think these conditions motivate you to try harder, to gather your energy and make a personal effort to deal with things as much as possible.

Later in his narrative Daniel refers to his ability to ask for assistance from the medical staff; however, “the problem is that when you get there, your condition doesn’t let you ask for anything.” Therefore, he turns his energy to construct an interpretive secondary control: the “Soviet approach” Daniel mentions refers to the educational approach in his family, in which he should be able to cope with difficulties on his own and mobilise his resources so as not to rely on anyone or share his troubles. This approach is very useful when one is isolated, like Daniel is during the hospital treatments. In fact, the conditions he is put in encourage such approach, and so he recruits notions of his intersectional identity, familiar aspects of parts of his identity to manage the situation. The familiarity of the coping mechanism, I claim, is what allows him to establish a sense of control and safety over himself. In other words, the objects lacking in the discussed space, are what catalyses Daniel’s construction of safety.

Home is an idea that addresses both the particular and the conceptual; individuals can utilise objects to construct their attachments; however, they can also develop their own interpretations of arbitrary surrounding objects to develop a similar sense. In this unique example, Daniel constructs his sense of safety by utilising the hospital’s poor conditions in the isolation room. Duyvendak (2011) adds that home does not need to be a “material, geographical place” (p. 36). In fact, the symbolic approach of
home he offers transcends the objective world; however, it is rooted in the existence of these objects in individuals’ mental structure and the meanings invested in them (Duyvendak, 2011). In other words, home is not solely a manifestation of the imagination, but is a signifier of the meanings that are produced by individuals (Duyvendak, 2011). The reconciliation Daniel constructs is the closest thing to safety he can reach under these conditions, and the familiarity of an aspect of his intersectional identity is what reassures him during his stay in the isolation room. This example demonstrates not only that there is no objective “home value” to the material world (Duyvendak, 2011) and that we can construct a sense of home out of objects and out of performance that promote attachments of feeling and meanings to a concrete space (Duyvendak, 2011), but we might do so in regard to absent objects as well. We can recruit familiar behavioural patterns to provide us with a sense of safety and control. I do not claim that Daniel can make himself feel at home during his treatments, but his strategy of performing his Soviet approach is the closest thing he can do to reach that feeling under these extreme conditions.

A sense of feeling at home, then, impacts individuals’ agency, particularly after a health disruption, and can determine the levels of belonging and strangeness constructed. In other words, the spatial aspect of trust can impact the social aspect of trust. As interaction with others would usually include their gaze, which is impacted by different spatial arrangements, then construction of trust (or distrust) with another social actor could be impacted by a sense of safety that is related to the spatial sphere.

**Trust and Distrust**

As discussed in Chapter 2, during biographical disruption different levels of belonging, that is of trust, are constructed and impact self-identity construction. Biographical disruption can undermine existing networks of belonging; trust then becomes an important notion as well, in relation to the discussion of safety. Biographical disruption can lead to a sense of trust being undermined, or create changes in the way it is constructed, as a health disruption is impacting the sense of control and intersectional process, hence affecting notions of safety and belonging and strangeness negotiation.

When we decide to trust someone or that someone is trustworthy, we essentially mean that the probability that they will perform an action that is beneficial, or at least not harmful to us, is high enough for us to consider engaging in some form of cooperation with them (Gambetta, 1988). Correspondingly, when we say that someone is untrustworthy, we imply that the probability is low enough for us to refrain from doing so (Gambetta, 1988). A health disruption means, for this context,
that new professionals will enter one’s life, and new relationships, which one will construct with new (and perhaps existing) individuals, will be impacted by the health disruption. Therefore, questions of trust are thus evoked. Can a person trust other individuals as before a health disruption? Does one’s health disruption impact others’ strangeness negotiation if stigma is involved?

A broad definition of the term trust was suggested by Barber (1983) who defined it as the conviction that the existing order in the world will remain intact (in Yamagishi, 2011), hence trust correlates with a sense of control. A more detailed definition relates to trust as a “psychological state comprising the intention to accept vulnerability based on positive expectations of the intentions or behaviour of another” (Rousseau et al., 1998, p. 395, in Bijlsma-Frankema & Costa, 2005, p. 261)—this definition suggests that the essence of trust is associated with risk taking as others’ behaviours may do us harm (Bijlsma-Frankema & Costa, 2005).

Navigating Risk and Uncertainty
Risk is a central factor that impacts the construction of trust. In fact, a wide variety of human activity is designed to manage events of breached trust:

   from coercion to commitment, from contracts to promises, with varying degrees of subtlety, mutuality, legitimation, and success, men and women have tried to overcome the problem of trust by modifying the feasible set of alternatives open not only to others, but also to themselves. (Gambetta, 1988, p. 217)

Contracts shift the focus from trust to distrust and the efficiency of sanctions, but in fact bind them together as people subject themselves to penalties, among them is to never be trusted again (Gambetta, 1988). Risk, according to Sztompka (2000), is parallel in many respects to trust: risk is the threatening possibility of future harmful consequences, and it echoes one’s responsibility (hence, ability) to prevent that horrific future. In that matter it suggests the agential commitment we have to our decisions (Sztompka, 2000). The relationships that the participants referred to, of course, were not officially revalidated after a health disruption, and in fact there was no obligation of others to stay and support them. However, when intimate social networks were able to provide needed support, and a sense of control, and trust was enhanced.

Risk and uncertainty, along with human aspiration for control, are intertwined in notions of trust, which in itself is a highly complex concept that research is struggling with exploring and analysing (Yamagishi,
Despite the challenges in deciphering the concept, it is clear to researchers that a group’s survival depends on its cultural attitudes towards cooperation in which trust can generate, as the latter improves the group’s adaptation to changes over time (Gambetta, 1988). In addition, there is little disagreement about the benefits of trust: according to Bijlsma-Frankema and Costa (2005), trust indicates the positive nature of relationships between social actors, and usually includes open communication and information exchange, along with psychological safety, commitment and mutual learning that can all lead to cooperation. As mentioned before, such binding agreement that links people’s commitments to each other is constructed for the purpose of elaborating resolution of collective problems; however, such commitment will not be sustained without sanctions for breaching obligations (Uslaner, 1999).

The future is unknown, simply because it hasn’t taken place yet (Sztompka, 2000). This does not mean that we do not attempt to predict what will happen in the world independently of our actions and what consequences there will be for our actions (Sztompka, 2000), as mentioned in the previous chapter. Our predictions are based on probabilities, which by definition “leave a margin of uncertain outcomes, the possibility that our predictions will not be borne out” (Sztompka, 2000, p. 19). Within the gap that exists between our expectations and the future lies the notion of trust that represents the uncertainty of the consequences of our behaviour in the societal world (Sztompka, 2000). In other words, “trust begins where prediction ends” (Lewis & Weigert, 1985, p. 976). Sztompka (2000) differentiates between the human response to the world of nature, which people aim to control, and the social world, in which we cannot control so hence must rely on trust to reach cooperation. Das and Teng (1998) specify that cooperation is based on probabilities that are calculated on the basis of the past; however, one must remember that people do not calculate probabilities solely on personal experience but also on previous cultural knowledge that may involve prejudice.

As uncertainty undermines the potential for trust or control, it is important to view which circumstances have higher potential to trigger trust: trusting another person always involves a risk (Sztompka, 2000); however, the degree of risk (the chances of winning or losing) and the stakes (the value of what is won or lost) might determine the potential for trust composition. If the risk is high and stakes are low then it would be wiser not to trust, and vice versa (Sztompka, 2000); however, life sometimes presents more ambivalent scenarios: if both risk and stakes are high, one might be inclined to generate trust to achieve their goals. A relevant example is provided by Sztompka (2000):
Look at the case of a patient deciding on experimental surgery against diagnosed cancer, even if the chances of success are estimated at 10 percent. He takes a risk, trusts the surgeon, because the reward of success—saving life—is extremely high, and the cost of withdrawing trust and not deciding on the surgery is equally extreme—inevitable death. (p. 34)

In other words, there are different levels of trust and for any given level the nature of trust is different. We may trust a doctor because the stakes are high, but we may withdraw from that trust if the interaction with that doctor indicates that they are not a trustworthy person. In addition, the individual who should put their trust in a professional’s hands has their own predispositions, such as their inclination to take risks or the ability to manage disappointment (Sztompka, 2000). At first glance it seems that distrusting involves less risk than trusting others as it allows people to construct a sense of control by relying on themselves. This notion is important since constructing trust takes much more effort than destroying it: if a person we trust is holding a gun or knife then this will make a considerable claim on the value of trust we have in them (Sztompka, 2000), but we may sometimes find ourselves trusting in others just because the circumstances coerce us to do so. Of course, the higher the level of trust, the higher the chances are that cooperation will take place, but the main point is that cooperative behaviour does not depend solely on trust, and the optimal chances of trust construction will vary according to the context (Sztompka, 2000). This does not mean that people trust each other only to pursue self-interest, but if people are embedded in an environment that does not reciprocate by furthering one’s interest as a result of trust, then people will be less inclined to trust each other, as suggested by Yamagishi (2011).

In a closer look, different types of trust that require different varieties of commitments can be identified (Sztompka, 2000). Among them are anticipatory trust that involves the belief that the other’s actions will be favourable to us (Sztompka, 2000). Another example is responsive trust that involves trusting others with control over an object that is important to us, and an explicit commitment to care for it (Sztompka, 2000). Another form of commitment is trust that evokes trusting others with whom we have intimate and familial relationships (Sztompka, 2000). However, an actual separation between the varieties of trust in everyday life is impossible, as trust is an entity that changes under different circumstances and is in constant construction between participants during interactions. Trust and commitment can be strong or weak, depending on the range of consequences that an action taken on the basis of trusting expectation will have (Sztompka, 2000). The duration of a relationship (and the
length of the interaction itself) will also impact a commitment based on trust (Sztompka, 2000). In addition, the possibility to withdraw from a commitment also affects the nature and quality of trust and commitment, as in the case of marriage without the option to get a divorce (Sztompka, 2000). Lastly, the level of risk has a dramatic impact on trust and commitment will be constructed according to the scope of possible losses incurred by the breach of trust (Sztompka, 2000). Despite that, it should be emphasised that risk does not operate alone: boarding a plane does not require a strong commitment and trust establishment with the airplane crew even though the loss in the case of a disaster could be terminal (Sztompka, 2000).

The next narrative section relates, though, to a constructed distrust towards one of the participants by another social actor. Maya met Shirley during her university degree, and wanted to be friends with her as they both shared a visual impairment; however, her attempts were unsuccessful:

> Shirley closed herself with the disaster she experienced... she lost her eyesight in her 40s, I don’t remember exactly, she wrote a book about it. I think she was a teacher before.... it was so many years ago. Around 30 years ago. I wanted to be Shirley’s friend very much. I felt empathy towards her, and I guess sisterhood because back then I wasn’t completely blind, but I knew what it was like. I had a close friend that was blind, and his wife, and I didn’t see very well of course, but she.... perhaps it took her some time to get to know people, I don’t know, I think maybe the fact that I was losing my eyesight gradually, and I travelled all over the sequence of sight and blindness, so I went through something that was easier than losing your eyesight at once.... And see, I have never seen well, so that was my natural state. So, it was easier for me to accept it. And Shirley’s rejection.... I didn’t like it very much, but we were not in the same MA programme; me and my friends were visitors in the course I met Shirley. With other people who can’t see I had a strong connection right from the start. We had a mutual interest, music, and we met with another couple, they were fine they could see, had no issues, and we were good friends, we met every year. And with Shirley, her attitude about her blindness was different, she considered it as a terrible disaster, and she had to get used to a whole new situation.

Maya describes in her narrative how she wanted to construct a sense of belonging with Shirley (I wanted to be Shirley’s friend very much). This notion of belonging should have been based on an intersectional identity of health disruption (I felt empathy towards her, and I guess sisterhood because back then I wasn’t completely blind, but I knew what it was like). At that time Maya was already near sighted and
had other friends who could not see. However, their relationship was based on another intersectionality—music. In this sense, their connection goes beyond an intersectional identity that is related to a health disruption, according to her, and this might stand for the potential of the connection she could have established with Shirley. However, Shirley rejected Maya’s attempts, and the question asked is why did Shirley not want to construct trust with Maya?

Trust holds a central importance in social life as it influences the potential for forming relationships that can contribute to construction of sense of belonging. Trust is designed to reduce uncertainty, to promote agency, and to function as a seismograph that indicates interruption in belonging construction. According to her, Maya did not give Shirley any reason not to trust her; however, the fact that a sense of belonging was negotiated based on an intersectionality identity that is related to health disruption was probably problematic for Shirley, as she lost her ability to see at a relatively older age and therefore was at risk of experiencing biographical disruption. Constructing belonging with another person who experienced a similar health disruption would trigger a different course of self-identity construction, as discussed in relation to stigmatised identities in the previous chapter.

Negotiating strangeness rather than belonging, as Maya’s narrative demonstrates, can assist people with managing intersectional identities that are stigmatised or unfavourable. Not trusting others may indicate mobilisation of one intersectional identity over another, as Shirley may have done. She chose to activate her agency to construct strangeness towards another social actor who is affiliated to “cultures of disability” and by doing so impacted her self-identity construction.

In fact, it is not that trusting is good and should be sought, and distrusting is bad and should be avoided (Sztompka, 2000). Strangeness has several important roles in regard to trust: despite its importance, at times it is wiser not to trust others.

Construction of distrust, like construction of trust, is an execution of social actors’ agency. Distrust involves a rational realisation that the other person simply cannot or will not carry the obligations and responsibilities required in a trusting relationship (Sztompka, 2000). In such cases it would be more prudent to carefully monitor the interaction and act more cautiously in order to protect oneself “against untrustworthy conduct and its dangers” (Sztompka, 2000, p. 107). Distrust leads to defensive measures such as avoiding contact, cutting off relationships and, in more extreme cases, using security measures to gain control over one’s safety (Sztompka, 2000). Hence, distrust is the agency that prevents a reproduction of the behaviour that has a high probability of causing damage. An ideal scenario suggests
that distrust would impact distrusted partners so much that they would be “pushed toward more cooperative, trustworthy behaviour” (Sztompka, 2000, p. 108). At other times, Gambetta (1988) suggests, we may wish not to be trusted, or distrust others, not only because we are too lazy to take responsibility for the commitment involved in trust, but because we prefer to compete with others. In many ways, life involves a struggle for survival and accordingly it is believed that competition is a basic texture of life, as the animal world demonstrates (Gambetta, 1988). However, competition cannot exist without trust; in order to compete, participants have to accept certain mutual rules by which they will compete (Gambetta, 1988). In addition, a measured amount of competition is beneficial in improving performances, triggering innovations, pursuing excellence etc. (Gambetta, 1988). In short, it has an equal function in the enrichment of the human behavioural repertoire and societal continuity (Gambetta, 1988). The biggest problem in this respect is finding the optimal mixture of cooperation and competition, especially when there is no model in the world that solves this issue: from natural selection to the invisible hand, no model suggests that those who trust are the survivors (Gambetta, 1988). The balance becomes something to aim for, but as other things in life, remains unattainable.

The participants in this research reported difficulties in constructing trust with others, at times, as a result of health disruptions, stigma, self-stigma etc. This was discussed in the previous chapter in regard to notions of control; however, this chapter views trust as the direct factor that impacts whether negotiation of belonging or strangeness will take place. To unpack this claim, the link between control and trust should be addressed first.

**Trust and Control**

Trust and control are wide and elusive concepts that are linked in a complex set of juxtapositions (Möllering, 2005). Both concepts have challenged the research, not only through their ambiguity, but also by the ways they are applied in the social world, and the complicated links they establish between each other. The previous chapter has already demonstrated that the need for a sense of control can be based on construction of belonging with another social actor, as in the case of vicarious control. However, individuals’ tendency to objectify others indicates that other social actors can be “utilised” to construct an illusory sense of control. In addition, another social actor may impact a construction of predictive control if they are trustworthy. As demonstrated in the previous chapter, a deliberate misdiagnosis would not have been effective had it been provided by social actors who were not trustworthy. Lastly, interpretive control can be undermined in case of a trusted social actor who is
discovered to be untrustworthy. In such case, an undermined sense of control would stem from one’s
disappointment in another actor, as well as disappointment in oneself for not anticipating a breach of
trust.

Perhaps the most basic link between trust and control is that they both assume each other’s existence. Some may claim that control is related to structure and trust to benevolent agency; however, that principle is not something that can be applied in the real world (Möllering, 2005). Rather, assuming the benevolence of another actor also assumes the existence of particular cultural structures in which such benevolence is valued. Thus, trust assumes the existence of control. Those who believe in the controlling quality of cultural structures must also assume that others will not exploit malevolently the relative freedom those structures leave to social actors (Möllering, 2005). Thereby, control relies on notions of trust.

As mentioned earlier, the construction of cooperation is based on the perceived probability and uncertainty of a partner’s behaviour, and the need to reduce the level of uncertainty can be satisfied by establishing a sense of trust and/or control (Das & Teng, 1998). However, if cultural structures and the social world provide a sense of order and control then what do we need trust for? If people can be encouraged to cooperate by deploying strategic alliances that promote their self-interests, or by using a socially acceptable degree of coercion (Gambetta, 1988), then why was trust invented? Firstly, Sztompka (2000) suggests that social order is unable to monitor and control everyone; therefore, moral order is constructed to trigger self-restraint and enforce cultural standards—a process that eventually leads to a wider range of collaborations and extends a freedom to pursue self and mutual benefits. Trust is not only the most realistic, economical, and viable social solution for the problems of control and the structure of society, but is in fact a scarce resource (Gambetta, 1988) that can be utilised to promote social developments.

As such, substitutes for trust do not provide the same benefits as trust does: people who do not trust each other will aim to replace trust with system of formal rules and regulations that have to be agreed on, enforced and sometimes even coerced (Sztompka, 2000). Coercion, as a form of control, is in common use as a means to achieve cooperation but is not in any way a suitable replacement for trust (Gambetta, 1988). Not only does it have different effects on people than trust, but it also ensures that if we do not expect to trust others then others will not put their trust in us (Gambetta, 1988). As the common paranoid behaviour among dictators suggests, coercion can lead to a particular cooperation
under specific circumstances; however, at the same time, it raises the probability of betrayal or
defection from a suffocating regime (Gambetta, 1988). When trust is missing then people may be
hesitant to initiate interactions with others, will follow safe routines and avoid innovation (Sztompka,
2000). Even when interacting with others, social actors will monitor the other side’s behaviour to ensure
that they do not intend to betray them (Gambetta, 1988). In other words, the general level of
mobilisation, activism, and freedom is lowered in a distrusting society (Gambetta, 1988). On the
individual level, biographical disruption can lead to changes in construction of trust, as a result of stigma
that may lead people to assume that others feel sorry for them, for example. Such a view can lead
individuals to aspire to “compensate” for a lower sense of trust with reconstruction of a sense of
control, as discussed in the previous chapter.

Möllering (2005) claims that the research done on trust and control is not well developed, and only a
small number of researches explicitly explore this problem. He argues that there is an initial and
superficial conceptualisation of trust as being the opposite of control; however, more recent researches
recognise the positive potential relationship between them. Thereby he suggests that trust should be
conceptualised as a continuous process (of [re]construction), thus it is not a static process as depicted by
qualitative surveys that usually aim to measure it (Möllering, 2013). This means that the relationship
between trust and control may vary under different circumstances: at times it seems that when social
actors increase the level of trust then the level of control reduces; however, on other occasions a
change in one does not lead to any influence on the other (Möllering, 2005). Möllering (2005) offers a
duality perspective in which “trust and control each assume the existence of the other, refer to each
other and create each other, but remain irreducible to each other” (p. 284). They form a reflexive
relationship when they establish a basis for positive expectations (Möllering, 2005), and as a result
people will let go a certain amount of control if they trust another person. The other way is also
accurate: people will try to take over some amount of control if they consider the other person
untrustworthy. Furthermore, Möllering suggests that trust produces control, and control produces trust:
that is, if we feel in control, and the other person does not try to undermine that sense, it would be
easier for us to trust them. However, if trust becomes the general norm in a society then people will
develop a sense of obligation, which is a form of control that is generated by society to trust others
(Möllering, 2005). Alongside that, control may produce trust as social procedures and regulation that
“can be contradictory and ambiguous or in some other way imperfect and open to interpretation” (p.
292), thus allowing the actor to use their agency for benevolent actions (Möllering, 2005). Trust and
control react to each other when both exist, but also when one component is absent. The following narrative section demonstrates how lack of control can develop an interesting relationship with the notion of trust:

Ella: There was a period in my life when my dentist became my therapist... Why? Because I have dental anxiety, and taking care of my dental health calmed me. Just made me feel relaxed. I used to say “I’m going to see my therapist; he’s going to take care of my teeth and I’ll be calm for a week or two.” Like, finding something that makes you feel good or calms some existential anxiety you have.... I feel safe at the dentist... I feel safe after the treatment, like I can feel safe anywhere after I took care of my teeth. Now I’ve scheduled an appointment because I realised I don’t feel “at home” because I didn’t treat them for a long time. Like, you see, it’s related to many things, when I don’t feel safe about something then I’m not safe about anything.

Ella describes how she utilises trust that is evoked by social roles (such as therapist or dentist) to establish a sense of perceived control. After going to the dentist, she is “relaxed for a week or two” as the treatment “relaxes some existential anxiety.” This is gained via an interesting process in which she lets go of control and submits herself to the care of her dentist. That situation leads, according to Ella, to a sense of control she may apply in other aspects of her life, as illusory control suggests. Moreover, she links a sense of perceived control (that is gained through the dentist’s treatment) to an object that can symbolise stability: it would be enough to mention the common dreams of crumbling teeth to understand this idea. Therefore, she revolves around losing and gaining control in a treatment context and relies on trust that social roles in a particular cultural context provide, and by doing so she establishes a sense of control in other contexts. Despite the fact that she does not negotiate belonging with the doctor this process is still relevant as it exposes a dynamic that is relevant for construction of a sense of control that is based on trust. In other cases construction of belonging is what allows individuals to form a sense of control:

Ben: For example, if someone says, “I want to celebrate my birthday at a restaurant,” and I did or didn’t check whether the restaurant is wheelchair accessible, to tell you the truth—I go anyway. Why? Well, I don’t have hurt feelings or shame about it. In most cases, two of my friends grab me, one on this side of the chair, and one on the other, and they lift me up those three or four steps. In most cases, there aren’t any steps anyway, but when there are, then it’s okay, I get help. Even today, I have a group of friends I meet every Thursday to play cards.
Sometimes we play in apartments with open rooftops, but access to the rooftop is difficult, you have to climb up one floor. And what happens is I get there, and two or three guys will grab the chair and lift me up.

Most research revolves around two approaches to the relationship between trust and control: the substitution perspective and the complementarity perspective (Bijlsma-Frankema & Costa, 2005). The substitution perspective suggests that both concepts hold reverse relationship, that is more formal control results in less trust, and vice versa—the higher the level of trust, the lower the costs of monitoring and other control mechanisms (Bijlsma-Frankema & Costa, 2005). The second perspective focuses on a complementary relation between trust and control and suggests that both concepts can be mutually reinforcing, and both contribute to the level of cooperation needed in a relationship (Bijlsma-Frankema & Costa, 2005). In the narrative section above, Ben describes a dynamic of trust that allows him to give up some level of control in regard to the access conditions in the public arena, but in fact provides him a sense of control as a result of the trust he puts in his friends. Das and Teng (1998) agree that supplementary relationship is a suitable description of the relationship between the two concepts, as trust and control levels impact independently and jointly on the level of confidence in a partner’s cooperation (Das & Teng, 1998). In this case, the social network of the speaker, that is based on notions of intimate trust and belonging, led to an intensified sense of control, despite the actual forfeit of sense of control as Ben does not know in fact if he is able (or not) to access a public institution. We could say that trust and control provide the same results in this case; however, that would not be accurate. The trust he constructs with others expands his options to participate in public events, even more than control would have allowed him in this case. His approach then allows him to choose strategies that involve integration to able-bodied culture.

Other participants have also demonstrated the ways trust and control intertwine with each other, and how a sense of belonging enhances a sense of control, as discussed earlier in this chapter. However, others who hold social roles that provoke an a priori sense of trust, as Ella’s narrative demonstrated above, did not help the participants to construct a sense of control at all times. A health disruption meant interacting with medical professionals who, at times, led to a decrease in participants’ sense of control, as will be discussed below.

Trust and control form complicated relationships: sometimes the one enhances the other as Ben’s narrative demonstrates. He portrays in his narrative a sense of belonging and trust that promotes a
sense of control. Sometimes principal trust that stems out of a social role can lead to a sense of control as in Ella’s narrative. It is clear that trust and control maintain relationships between themselves; however, they are complex and formed differently in varieties of contexts. The interlink between trust and control is, in fact, one of the core dynamics of the CSC model, as choice of one or two means would impact the intersectional process, which would impact one’s self-identity construction.

The Impact of Social Roles on Construction of Trust

Sztompka (2000) claims that different social contexts require different levels of trust, as we will not trust a close friend, a business partner or a service provider in the same way, simply because they have different social roles in our lives, hence there are different sanctions and expectations that involve those roles. Social roles are related to different levels of trust and allow us to presuppose what type of trust should be generated in the first place in regard to the cultural values others hold (Sztompka, 2000). Some roles evoke trust such as mother, friend, doctor of medicine, university professor, priest, judge, etc., while others imply a priori distrust, for example a taxi driver, used-car dealer, prostitute, prisoner etc. (Sztompka, 2000). Clearly, the cultural context impacts the level of trust given to different roles. For example, while I was living in New Zealand, the resignation of the Prime Minister in 2016 was not highly questioned by the public (as it may have been in Israel had it happened there) due to high levels of transparency in the public sector of New Zealand that lead to relatively high levels of trust in politicians’ motives.

Gambetta (1988) adds that trust will be set not only according to social roles but also to individual prepositioning (for example, one’s inclination to take risks or degree of tolerance to potential disappointment); in this respect he suggests that social actions that are dependent on others’ cooperation are independent of trust: for any given level of trust, they may or may not be initiated depending on particular predispositions and interests (Gambetta, 1988). For example, as mentioned before, trust is usually higher when risk and the cost are relatively high (Gambetta, 1988). Some social roles include a complex performance that generates trust: medical doctors are expected to be professional and effective while expressing sympathy and helpfulness (Gambetta, 1988). If they perform only one of the tasks successfully then they might not be trusted by their patients. Moreover, in a research conducted by Sztompka (2000) he discovered that almost 60% of the participants were willing to trust a doctor who expressed care and empathy, even before they had demonstrated their professional abilities (Gambetta, 1988). This indicates that first and foremost the nature of interaction
that doctors establish with their patients has a crucial impact on the level of trust built, regardless of the doctor’s ability to prove s/he has the required skills and knowledge.

Medical professionals are relevant to this research and especially to notions of trust: as part of their journey with health disruptions, the participants had to negotiate not only their identity, but also the levels of trust they could put in medical institutions and professionals. A form of an abstract trust is directed to those who carry social roles, as mentioned before, but also to institutions and organisations such as schools, universities, the army, the church, the justice system, the police, hospitals etc., and can vary over time (Gambetta, 1988). Abstract trust, then, can be deformed or reconstructed when people are engaged in interaction with professionals from one institute or another. People may hold a general view that such institutions are designed to serve individuals’ needs, and thus believe that following regulations and rules will lead to the best results (Gambetta, 1988). In fact, this notion of trust could be claimed to be based and extracted from a more general and abstract concept of trust in the overall qualities of the social order (Gambetta, 1988). However, almost all participants had to manage situations in which an abstract trust they had in medical professionals was challenged and undermined:

Adam: I arrived at the hospital 3 weeks later to take the stent out, I postponed it as much as I could, I went to have it taken out about a month later, after I couldn’t walk anymore because the stent was moving inside.... So, I went to the hospital and it turned out [that the procedure] wasn’t under full anaesthesia, in fact it was without any anaesthesia at all. They just go for it, live, and the doctor says “Let me give you some anaesthetic,” and this stuff doesn’t work at all, a total sham, it’s all in your head, and it was like a delivery room, everyone in the corridor heard me [screaming] and the doctor gets angry and says, “Calm down, you’re disturbing me.” I tried explaining that I had been wounded in my previous surgery, but he didn’t even care. I asked for full anaesthesia—“There is no full anaesthesia here” [imitating a Russian accent] “You’re here and that’s that.” And you don’t have any choice because you can’t walk anymore.

Shira: You’re not really in a negotiation position, either.

Adam: Exactly. And of course, it started bleeding again for a week or two... To make a long story short, I was on pain killers for 2 months, and once I stopped, I started having issues with my stomach, which had probably developed long before but I didn’t notice because of all the pain killers, so once I stopped with the painkillers, I started having stomach aches and intestinal
problems, gastro and infections and such. And it turned out that the pills I was given were
damaging to the stomach, that they caused ulcers, lots of problems.

Shira: And you were not informed of this in advance?

Adam: No, no one bothered to tell me, I only discovered this later when I looked it up online and
discovered that it damages the stomach. They say you need to take it with food, but no one
knows why, so yes... I had complications for 6 months and it was a total mess.

Adam’s health disruption was, according to him, a result of medical malpractice that led to physical
complications, and loss of job and relationships. He first mentions that he postponed his arrival to the
hospital to take the stent out, probably because of a negative experience he had during his surgery (I
have been wounded in my previous surgery), hence his levels of abstract trust in the institution’s
professionalism were low to begin with. His postponement can be interpreted as breach of trust at his
end since as a patient he has to follow a medical protocol as well. However, low levels of trust brought
him to make an independent decision not to follow the treatment schedule and make an appointment
only when there was no choice, as he realised he “couldn’t walk anymore because the stent was moving
inside.” Such course of action can lead to mutual loss of trust: the patient doesn’t follow the doctor’s
orders as they have little trust in the doctor’s skills, so the doctor may lose trust in the patient’s
motivation to follow their instructions, and as a result the recovery process may be flawed. It should be
noted that Adam makes an active choice to postpone his appointment as a result of lack of control he
senses as a patient: not only he was wounded during his surgery, but his request for anaesthesia is later
refused. He tries to communicate his need to have anaesthesia but is silenced by the doctor. This is a
description of a situation in which no trust is gained, and no sense of control is achieved, thus
strangeness begins to be constructed.

Adam describes in his narrative the lack of information about the medication he was prescribed, which
should have been provided by the treating doctors, that led to physical complications and the
unnecessary pain he experienced for 6 months. This narrative section portrays a breached abstract trust
with medical professionals that further impacts the described interaction with a particular doctor. In
addition, he defends his decision-making process and interaction with the doctor not only for their lack
of potency but also by his lack of choice in the situation. The doctor in this narrative section does not
express empathy or professionalism, according to Adam. In fact, the doctor is angry at his patient so
there is little hope at this point for trust construction within the described interaction. Adam is forming
the doctor’s identity through the narrative as an untrustworthy professional by mimicking his foreign accent and marking him as a stranger, and by doing so aims to achieve empathy (and construct belonging with) the listener who was born and raised in Israel.

At this point it is important to remember that Adam is describing a situation that denies a sense of control; in this view it could be argued that the narrative construction that Adam is making is (amongst other processes) an act of gaining a sense of interpretive control over the described situation. More specifically, by characterising the doctor as an outsider, Adam can position himself as an (insider) victim. This process becomes even more interesting if we consider Bauman’s (1997) words:

> The less people control and can control their lives and their life-founding identities, the more they will perceive others as slimy, and the more frantically they will try to disentangle, detach themselves from the strangers they experience as an enveloping, suffocating, sucking-in, formless substance.” (p. 28, in Marotta, 2000, p. 123)

A lack of control and process of objectification that prevents individuals from expressing their voice and needs during interactions can be somewhat compensated for by marking others as strangers and objectifying them. This process is relevant for any cultural contact understanding as two groups may mark each other as strangers and belonging negotiation would then not be available due to issues of control and trust.

A sense of distrust may indicate a sense of loss of control (Sztompka, 2000) that may also be compensated for in specific contexts. As we operate in a risky and uncertain world it is acceptable that not everyone can be trusted; so, what other substitutes can social society provide to solve the problem of distrust? As mentioned earlier in this chapter, control can be utilised to compensate for a sense of lack of trust. For example, Sztompka (2000) suggests that bureaucracy, procedures and cultural rules can regulate behaviours in a society; however, they do not always have a similar affect to trust. In fact, the more a society depends on rules to regulate interactions, the fewer conditions there are to construct trust between its members (Sztompka, 2000). In fact, when trust cannot take place then the discourse shifts from agency to passive acceptance of fate and god (Sztompka, 2000). If the dominant culture is of distrust, or trust is lacking in intergroup relationships, then a behaviour that should lead to sense of control would be more dominant than behaviour that aims to provoke trust: for example, those who seek to execute an active sense of control can decide to manipulate others and to become untrustworthy (according to the accepted norm in a society with low levels of trust), or to take into their
hands a direct supervision and control of others (for example, the use of surveillance cameras, body guards etc.) (Sztompka, 2000). The last mechanism suggested by Sztompka is ghettoisation, that is to build clear boundaries around a group and deny access to anyone who does not belong, hence is untrustworthy. However, such solution leads to xenophobia, hostility towards others and isolation (Sztompka, 2000), and thereby will reduce the possibility for construction of intergroup affiliations.

**Trust and/as Agency**

A central discussion about the notion of trust relates to its role as a practice of agency (Möllering, 2013). That is, trusting is not simply dependent on social contexts, but it also reconstructs, in a reflexive process, the rules in which it is embedded (Möllering, 2013). We have to take into consideration that when an actor decides to use their agency benevolently, they do so within the frame of a social structure that leaves room for specific types of benevolence within a specific context of cultural structure (Möllering, 2005).

This could also be viewed the other way around: an actor’s benevolence indicates the cultural gaps in which their agency is constructed, hence control and trust add another dimension to the link between them. Gambetta (1988), on the other hand, does not exclude the role of trust as agency, but claims that trusting another person is not induced at will, and in fact can be considered as a by-product of ongoing relationships. Both agree, however, that trusting others is an active choice to take a risk; however, it is “unclear whether risk is an antecedent to trust, is trust, or is an outcome of trust” (Mayer et al., 1995, p. 711 in, 2012, p. 27). This perspective implies that past risk behaviour can be viewed as “an antecedent impulse to present risk taking, and future risk taking as the outcome of present risk taking” (Lewis & Weigert, 2012, p. 27). If the risk is lucrative and trust is evoked, then it may motivate the participants in the interaction to initiate positive behaviour towards each other (Sztompka, 2000). All in all, trust liberates human agency, and triggers creative and innovative social behaviour (Sztompka, 2000). The level of uncertainty then is reduced and the range of actions that may increase trust expands (Sztompka, 2000).

This is not only an ontological comment about trust, but also a methodological one: during the interviews that were conducted for this research, there was a need to establish trust between the researcher and participants. The notion of cultural similarities that impacted the ability to construct trust were discussed in the methodology chapter, but the following metaphor may further explain the notion of trust: people need to be heard, but also to know enough about the interviewer to feel safe to
expose themselves. The interviewer is not only engaged with the conversation, but also maintains an imaginary bonfire which represents the narrative provided by the participants: when needed, the interviewer adds wood to the fire, tells about themselves or provides feedback to the speaker’s words. At other times the flames require oxygen and listening, and sometimes a small modification of the firewood, in the form of open questions, is required for better oxidising. It is a complex and delicate process that cannot be perfected. It involves emotional, cognitive, behavioural and cultural knowledge that always lacks in the fine details.

Shira: How did you begin trusting your caretaker? Was it difficult to trust a stranger at first? How did you begin trusting him?

Ben: On the contrary, I go the other way around. When I meet a new person, it doesn’t matter if they work for me or not, at first I have full confidence in them. I give you my full trust, do whatever you think. But if one time I’ll catch you doing something (out of bad intentions) then it’s over in that moment. No second chances or anything. I give you full credit with my eyes closed, really, at first, I trust people 100%.

As demonstrated by Ben in the above narrative section, trust can operate as an agency; however, Yamagishi (2011) asks—how come such agency was developed by human society, if it involves risk taking that might jeopardise one’s survival? After all, trust evaluates a partner’s trustworthiness based on incomplete information and hence is biased and inaccurate, which implies that a high level of general trust is adaptively disadvantageous (Yamagishi, 2011). In fact, in a hypothetical world in which people have a super microcomputer implanted in their brain to boost calculation power far beyond the limit of biological information processing capacity, one would hardly ever need to trust anyone else (Yamagishi, 2011). Such argument implies that having a high level of general trust in people, as Ben demonstrates above, actually indicates a naïve behaviour (Yamagishi, 2011). However, based on a series of experiments Yamagishi conducted, he claims that general trust emerges as a by-product of social behaviour that is consciously adaptive to the environment, if that environment makes general trust an advantageous trait to acquire. In fact, people trust or distrust others not only because of limitations in their cognitive capacity to process information, but because there are cultural contexts in which trusting others leads to a beneficial outcome (Yamagishi, 2011). This, according to Yamagishi, raises a potential problem since high trusters are considered to be naïve and gullible. This is basically wrong, he claims, as according to his researches high trusters identified information that revealed other people’s lack of
trustworthiness more sensitively than low trusters did. In a way, Ben presents the same claim: his starting point is to have a high level of trust in people, but he emphasises that if that trust is breached “then it’s over in that moment. No second chances or anything.” Low trusters, on the other hand, were initially insensitive to information that indicated a partner’s untrustworthiness, but after experiencing disappointment at a partner’s lack of cooperation, they became oversensitive and hesitated to trust their partner even after the latter began to cooperate (Yamagishi, 2011). This suggests a core limitation in the social behaviour of low trusters. The results suggest that those who trust others in general and consider people as honest and fair to others, those who believe in the effectiveness of cooperation and are considered by others as trustworthy, are more accurate in detecting if others are trustworthy than those who hold low levels of trust. This is because the latter would consider others as liars and thieves, and believe that fairness and honesty are meaningless and are also considered to be less trustworthy themselves by others (Yamagishi, 2011). These experiments not only indicate that those who are trustworthy hold higher levels of trust in others (and vice versa), but also that people who trust others are better at understanding the behaviour and characters of others than those who have low trust in others (Yamagishi, 2011). In other words, those who have a high level of trust are also characterised by higher social and emotional intelligence (Yamagishi, 2011).

Such intelligence is the ability to understand one’s own and other people’s internal states and use that understanding in social situations in a variety of ways, such as the ability to control their emotions, empathise with other people and establish social relationships (Yamagishi, 2011). Those with high trust invest cognitive resources to decipher if others are trustworthy or not, and as a result become more sensitive to information related to others’ trustworthiness (Yamagishi, 2011). Moreover, those with a high level of trust have more opportunities to develop social intelligence as they are more likely to become vulnerable as a result of trusting others because they can be exploited or deceived (Yamagishi, 2011). Furthermore, those who are sensitive to information that indicates if the other is trustworthy or not will not suffer serious damage if they find out later that their judgement was incorrect and will not become untrusting of others as a result (Yamagishi, 2011).

But what happens to those with low levels of trust? They are at risk of suffering severe loss when they are disappointed to realise that a person they thought to be trustworthy is not such a person (Yamagishi, 2011). The best way for socially unintelligent people to avoid such situations is usually to avoid social uncertainty or contact with strangers as much as possible (Yamagishi, 2011). Yamagishi’s
(2011) theory, then, suggests that society benefits from people who are socially intelligent and have a high level of general trust in others. As mentioned before in this chapter, if most in a society were low trusters then most people would withdraw from interacting with others and thus reduce the chances of the group’s survival (Yamagishi, 2011). Such people would usually assume that “everyone is a thief”; however, they should take into consideration that this notion would impact future interactions they would have with others, unless they are able to establish relationships “in which benign behaviour from partners is assured” (p. 126). Biographical disruption can lead to low levels of trust and thereby lead to strangeness construction as part on social actor’s agency. However, as mentioned before, social actors may also utilize their agency to manage this impact on belonging negotiation, despite external problems, such as stigma.

Sztompka (2000) views trust as an agency as well, and builds his argument based on two possible responses for uncertainty:

- hope, or its opposite resignation, which is considered to be a passive and not a rational response.
- confidence (or predictive control, as suggested in the previous chapter), or its opposite doubt, that is a more focused and to some extent justified faith that something good will or will not happen.

As such, trust can be described as an emotion of assured expectations; a situation in which one is not active but is able to produce a contemplatively observation of the situation (Sztompka, 2000). Disappointment of such confidence will allow people to place blame “others, the regime, the system, the propaganda, the falsified information, the faked credentials, and so forth, but not oneself” (p. 24). These responses fall into the discourse of fate and determinism that refer to something that takes place away from social actors’ ability to influence (Sztompka, 2000). Trust, on the other hand, falls within discourse of agency in which one actively anticipates and faces an unknown future (Sztompka, 2000). This form of agency has two aspects: risks and commitment. As we trust we take risks and gamble upon others’ future behaviours (Sztompka, 2000), and as mentioned before, when we decide to trust others, we risk that people will behave in a matter that might not be benevolent, or even harm us; we risk experiencing negative psychological experiences due to our lack of judgement that may be felt as grief at the realisation that people are worse than we believe (Sztompka, 2000) and that the world is not a safe place (Janoff-Bulman, 1989). Another disappointment is related to more intimate relationships like friends, family ties, lovers etc., where the amount and quality of trust is higher and in which the trustee
is aware and accepts a moral obligation of trust (Sztompka, 2000). Trust in such relationships is so strong that if it breaks then we may experience severe damage to our sense of control and to aspects of self-identity, as trusting intimate others is a form of agency that may be considered as an assumption that we can anticipate the future (Sztompka, 2000). The result of this mapping is the acknowledgement that risk, control and trust are forever intertwined in suggestive dispositions of agency and passivity.

Lastly, perhaps the most important aspect of trust as agency is provided by Sztompka (2000): “Trust is more than just contemplative consideration of future possibilities” (p. 26); trust also involves taking responsibility over the unwelcome future that we have actively brought upon ourselves.

Maya: I have a friend who specialises in animal behaviour and training. She asked me, “Would you like to have a guide dog?” That was 20 years ago, when I lost my eyesight, I said, “I considered it, but I’m not sure I could trust a dog.”

Shira: Why is that?

Maya: I wouldn’t be able to trust it because I don’t trust anyone.

Shira: Why?

Maya: Now that is a good question. Why? You see, many years ago I used to photograph, and I told my niece I would really like to go to London for a week, so I could take pictures before I completely lose my eyesight. So, we went there, I don’t remember how long ago it was, and we constantly walked arm in arm. One time we were at the Princess Diana Garden, it was so beautiful. And all of a sudden, I couldn’t find my niece, I couldn’t see her and I felt a terrible anxiety.... I was alone in a strange place... If it happened here, it wouldn’t have been so bad, I’m used to walking by myself a lot, but not in a strange place. You’re in an unknown place, you don’t even know how to ask for directions because you have to take the tube and who knows.... Anyway, after returning to Israel, for a long time I felt like something was missing on my arm, because we would walk arm in arm in London.

If we had power over others, then we would be able to enforce our expectations and coerce others to act as we wish (Sztompka, 2000); however, such a scenario is relatively uncommon in society. We must understand then, Sztompka (2000) adds, that not only control and risk are involved in trust but also freedom of choice: “an actor’s trust in others presupposes the freedom of action of others” (Barbalet,
The niece Maya couldn’t find in the Princess Diana Gardens demonstrates this idea; it is not clear where the niece went or how the two women got separated, but the situation displays the principle that any interaction can involve expectations of the other that are not always fulfilled. In this case Maya speaks of a lack of ability to trust others (in this case, a guide dog) due to previous disappointments that led to “a terrible anxiety,” hence a drastic experience of loss of control. Maya found herself in a foreign land where “you don’t even know how to ask for directions.” This experience was utilised in her narrative to explain why she does not trust anyone, people or animals, to ensure her safety. It should be noted that Maya is speaking of a principal distrust on an intimate level that requires a high level of trust and dependence (in a niece or a guide dog). However, when she walks the streets of Israel by herself, she is able to establish lower levels of trust and these are the interactions that allow her to manage her health disruption. Therefore, principal distrust should be differentiated according to the circle of trust it is related to, and its impact on belonging, strangeness and self-identity construction.

Trust, then, is an act that acknowledges people’s freedom to disappoint us. In fact, its definition as an agency stems from the agency of others. The reason we cannot control others is due to human singularity that leaves room for human choice and agency, that is others’ thoughts, dreams, intentions etc. (Sztompka, 2000). People always have a choice, even if it only amounts to taking their own lives (Frankl, 1946). As such, Gambetta (1988) claims it does not make sense to hold a principal trust or distrust in others (as Maya does), as it represents “predispositions to assign the extreme values of the probability and maintain them unconditionally over and above the evidence” (p. 216). Those who hold principal distrust, a paranoid and obsessive notion, will suffer from loss of potential opportunities for new relationships, or abandonment of existing beneficial relationships (Gambetta, 1988). This phenomenon may characterise those who, under new conditions and during their journey of biographical disruption, will choose solitude as a strategy. As such, principal distrust may not reconcile an identity construction process that takes place and may even problematise it.

The key to managing a potential development of principal distrust lies within an existential sphere—suspension. Gambetta (1988) suggests it represents a time of “mistrust” that exists in neutral situations, when both trust and distrust are suspended, and clear expectations are lacking. He claims it is a temporary intermediate phase in the dynamics of trust or distrust construction (Gambetta, 1988). Suspension is the process through which actors deal with the possibility of trust violation and must
address the tension between agency (trust) and structure (control), hence notions of uncertainty and doubts are involved in the process (Möllering, 2005). In this sphere we do not trust or distrust others, but we mistrust them (Gambetta, 1988); it is a neutral situation in which construction of trust or distrust is suspended.

Trust is an expression of agency of individuals that burdens them with the responsibility for their own uncertainty about implications of belonging construction. This uncertainty is rooted in the social world and indicates other social actors’ prerogative to choose as well. Health disruption may problematise trust construction and thereby belonging and strangeness negotiation. This process is complicated and multi-layered, and impacts directly self-identity construction.

**Trust and a Sense of Belonging**

Circles of trust are gradual, expanding and represent a range from the most “concrete interpersonal relations, toward more abstract orientation toward social objects” (Sztompka, 2000, p. 42). The narrowest radius symbolises the trust we have in those we consider family, and is characterised by the strongest intimacy (Sztompka, 2000). The next circle includes people who we know personally and interact with on a frequent basis (Sztompka, 2000). At this level, trust would still involve a relatively high level of intimacy and closeness (Sztompka, 2000). The wider circle consists of other members of the community who are not directly encountered, and the notion of trust that is constructed with them is part of a collective that exists mainly in our imagination (Sztompka, 2000), as discussed in the previous chapter. Modern society and technology provide a virtual circle of trust as well: these are the “idols, celebrities, pop-culture heroes, famous politicians [that] seem to be known to us personally and intimately” (Sztompka, 2000, p. 42) and yet have gained our trust. Circles of trust include those who are familiar to us, those with whom we have things in common, in different levels and different forms; the quality of trust we have towards different people reflects a sense of belonging that can be constructed within these relationships.

What Sztompka (2000) defines as the tension between trust and distrust (for example: one may trust their family and friends, and distrust politicians) can in fact be considered as the tension between belonging and strangeness. We belong to those whom we trust, and we aim to construct strangeness towards those whom we distrust. In this respect, Möllering (2013) adds that “trustee and trustor keep on constructing their identities together in the process of trusting” (p. 294). That is, trusting others
signals and confirms people’s willingness to belong to a collective (Möllering, 2013), and construct their self-identity accordingly.

Trust assists with maintaining in-group forces of identification as a basis for positive expectations between group members, thus trust builds on and sustains personal and collective identities (Möllering, 2013). As such, trust does not hold a moral value: there is no intrinsic quality of trust as good or bad (Sztompka, 2000). Trust, in other words, could be based on negative shared values, such as chauvinism or racism; however, it will still function as a means to trigger cooperation of people to achieve a mutual cause. It appears that trust is a social tool for belonging construction, and not the other way around. As such, trust can be a localised, particular and a dividing means for exclusion (Sztompka, 2000).

**Being Trusted by Others**

An aspect of trust that is crucial for belonging construction is the ability to be trusted by others (Gambetta, 1988). Precommitment operates as a device whereby we can impose some restraint on our behaviour, and by doing so restrict the extent to which others have to worry about our trustworthiness (Gambetta, 1988).

> Ben: I went with my daughter to the mall the other day, and we went in one of the stores, while the cashier was sitting at the entrance, so as I came in, I said, “Hi, how are you?” My daughter stopped and asked me, “Dad, do you know her?” I said, “No.”—“So why did you say hi to her?” I said, “Because she works here.” Later I told my daughter, “If you knew how much power there is in a kind word and a smile, which you can always give away for free because it has such a positive impact, much more than if I started shouting or say this and that, because once you start shouting other people feel antagonised, and here I walked in smiling—’Hi, how are you?’ As if she were my friend, even though I didn’t know her, and had never seen her before in my life.”

In the narrative above, Ben describes how he signals the potential to develop trust in him: despite the fact that he describes an interaction with a wide circle of trust, it is utilised to construct self-identity based on trust establishment within other circles of trust. However, different circles of trust and belonging can impact each other as his daughter witnessed his attitude and was provided with the logic behind it. Ben chooses trust construction as he thinks trust will benefit him more than trying to establish control by objectifying the other person (and constructing strangeness). In fact, he believes in constructing belonging by establishing trust as this leads to an optimal usage of his agency:
If you knew how much power there is in a kind word and a smile, which you can always give away for free because it has such a positive impact, much more than if I started shouting or say this and that, because once you start shouting other people feel antagonised.

Being granted someone else’s trust provides a temporary suspension of regular cultural constraints and inhibitions, that according to Sztompka (2000) can release the social monitoring and allow elaboration of agency, of nonconformity and freedom of action. An additional benefit could be that being actively trusted by someone can function as an argument for others to trust that person as well (Sztompka, 2000). Being trusted or trusting others has an impact on construction of both collective identity (belonging) and self-identity: those who trust others do so as part (and according to cultural models) of their collective norms that encourage trust building, however, at the same time, trusting others may benefit by the sheer satisfaction of giving others a credit of trust (Sztompka, 2000): “Like making a gift, it makes one feel magnanimous, generous, and benevolent, and through a reflected glow of the recipient’s gratitude raises one’s self-esteem” (Sztompka, 2000, p. 35).

Maya: It was so gradual no one even realised how much I couldn’t see. When you see someone, and they manage independently... My son used to say, “Mom, you walk like you can see.” And he would get angry at me for that. Angry. “You rush forward like a tractor.”

Shira: Why was he mad at you?

Maya: Because he knew I couldn’t see.

Shira: But why did it bother him?

Maya: Because he was worried that something might happen to me.

Shira: But he could see that nothing had happened he could see you were doing well.

Maya: I know, but a child always worries for his mother, more than his uncles, for example, who are always busy with their work and don’t visit on a daily basis.

In a similar manner to notions of control and home, trust sometimes also stems out of (and is maintained within) the mental sphere. In fact, despite the importance of trust in self and collective identity construction, it sometimes emerges out of different interpretations, that could even claimed to be misinterpretations, as Maya demonstrates in the narrative section above. Maya interprets her son’s anger at her as a sign for love and worry for her safety. Such interpretation indicates that he does not
acknowledge her achievements, what could have led to construction of strangeness between mother and son. However, her interpretation of the situation, in fact, enhances potential for belonging construction.

As people act based on beliefs, knowledge, memory and interpretation of past experiences, the state of their future knowledge (along with the beliefs they will hold, interpretations they will construct and by which they will act in the future) cannot be predicted, before they actually conceive it (Sztompka, 2000). Different and sometimes random signals may be “interpreted” by one side as an inclination of the other towards an establishment of trust (or distrust); however, these signals may be the result of incorrect interpretations (Gambetta, 1988) that are based on cultural models a person incorporated into their identity. For example, the notion of “live and let live” which flourished between enemy soldiers in the First World War may have resulted from the fact that soldiers on both sides stopped shooting at regular intervals, because they happened to have their meals at the same hours of the day (Gambetta, 1988); this random act led to a possible misunderstanding that was interpreted as “a stable cooperative abstention from mutual injury” (Gambetta, 1988, p. 221). However, a confidence that may have emerged accidentally can subsequently be learnt, and the soldiers developed the means to signal the “enemy” their predisposition to establish cooperation (Gambetta, 1988), which led to the myth of “the Christmas Truce” in 1914. Moreover, according to Möllering (2005), when forming expectations of others, social actors take inseparable influences of structure and agency into account, hence the process of interpretation itself is an agency that affects the understanding of an interaction and one’s behaviour during it. Maya, for example, interprets her son’s words (You rush forward like a tractor) as a statement of concern although it could have been interpreted as an expression of lack of trust in her abilities, and thus led to potential for strangeness construction.

As mentioned earlier in this chapter, the option of cooperation without trust is subject to the external context that depends on the force of the mechanisms that affect our abilities to choose to cooperate or not (Gambetta, 1988). If the pressure to act is great, for example, then cooperation will be formed even if the level of trust is low, and people may generate means of wishful thinking or reduce cognitive dissonance. By doing so they can assemble a deceptive rearrangement of beliefs that leads to

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8 A series of widespread unofficial ceasefires along the Western Front of the First World War around Christmas. During the unofficial ceasefire, soldiers on both sides of the conflict emerged from the trenches and shared gestures of goodwill.
cooperation (Gambetta, 1988). Strategic alliances, as suggested by Das and Teng (1998), demonstrate such a state. Strategic alliances represent a paradoxical situation as social actors are assumed to pursue their own interests while being simultaneously required to care for the other’s interests as well (Das & Teng, 1998). In such cases a fine balance between competition and cooperation should be kept (Das & Teng, 1998). In general, as long as both social actors are satisfied with the outcomes of the arrangements, cooperation can be constructed (Das & Teng, 1998).

Regardless, Sztompka (2000) suggests that societal actions can take place whether or not people trust them. A package, for example, will arrive at its destination whether we trust the postal services or not. It is not so much that trust is not involved in the situation, as that it would not seem to be a precondition of cooperation (Gambetta, 1988). In this respect Gambetta (1988) rightfully claims that “actions which are dependent on other people’s cooperation are independent of trust” (p. 219). However, this research suggests that the medical context requires high levels of trust between medical professionals and patients, as medical care is based on recurring and ongoing interactions between them. The probability that another social actor “will not act in a harmful way is raised by the understanding that mutual interest makes defection costly enough to be deterred” (p. 22). In this sense it could be claimed that a principal assumption that others will breach trust, can lead to this very result. A significant health disruption can lead to a similar process and shift the ways individuals construct trust with medical professionals, for example. In some cases, abstract trust could be breached, and further interactions with medical professionals would be impacted by it, as demonstrated by Adam’s narrative.

Even more tragically, people may think that others will not trust them to cooperate, and thus will not attempt to trust others (Gambetta, 1988). Thus, trust can be defined as a problem of communication. Gambetta (1988) suggests that even when people have perfectly adequate motives for cooperation they still need to know about each other’s motives and to trust each other, or at least validate the effectiveness of their motives. Trust then can be undermined if communication prevents the original meanings from being fully accepted and correctly interpreted by the other actor during social interactions. Consequently, Gambetta suggests that we should not focus on trust but rather on cooperation and promote the optimal conditions for communication that should be elevated above all constraint and self-interests.

The different levels of trust people construct in different circles reflect not only their belonging but also the path on which they design their agency. Like trust, belonging has different levels and it is not
required to establish the same trust (and as a result, belonging) with everyone. In fact, as people change
their positioning on a belonging–strangeness axis, they simultaneously do so on an axis of trust–distrust.
Interactions determine one’s ability to construct higher or lower levels of trust, principal distrust,
abstract trust and more. These interactions are affected by life experiences and schemas that are
embedded in self-identity and impact social actors’ acculturation strategy formation.

Summary
Both home and trust stand as important aspects of what compounds a sense of safety. As discussed in
this chapter, home reflects a spatial facet that is related to safety, while trust is linked to the social
aspect of safety. Home is a space that is under one’s control, as mentioned in the previous chapter, and
its construction is triggered by notions of choice, as Ella and Daniel’s narratives demonstrate. When a
sense of safety in this respect is undermined, it has a direct impact on a sense of control and individuals’
agency, and thereby their self-identity construction.

To this a sense of trust is added that can be (but is not necessarily required) constructed for the purpose
of cooperation. In general, the advantages of trust have been discussed in this chapter, but at the same
time it is suggested that it is not required during different kinds of life events and interactions. Trust is
sometimes constructed as a result of misinterpretations, or is based on principal trust or distrust, and as
such demonstrates that it does not always be grasped in objective reality.

Construction of safety, then, is linked to individuals’ need to sense control and have a direct effect on
one’s belonging and strangeness negotiation and therefore one’s self-identity construction. People who
experience biographical disruption as a result of a health disruption have to cope with questions that are
related to their sense of safety, and the trust they are able to construct with others in a new context
impacts their biographical work. This would be particularly the case if power relations in a new context
are not in favour of a person who is experiencing a health disruption, as they have to manage a stigma
that is attached to their identity by others.

After examining the two main principles that are utilised to construct belonging and strangeness, the
next chapter will review the choice in trust and/or control, along with choice in intersectional identity
that impacts a process of belonging/strangeness negotiation. This will be done to explain the dynamic of
self-identity construction after a disruptive event, and examine the choices individuals make when they
activate their agency during belonging and strangeness negotiation.
Chapter 7: Choice

Introduction

When thinking about a discourse that identifies people who experienced health disruptions the notion of narrowed scope of choices comes to mind. However, as mentioned before, people always have the ability to choose, even if their choices are limited by cultural structures. Therefore, it was necessary to focus on elements of choice that are available to people who experience biographical disruption and offer a framework that examines the choices made by social actors to establish belonging and strangeness by utilising trust and/or control. All elements reviewed so far are in an endless intertwined relationship, as will be demonstrated later: trust is used to establish control that can lead to belonging; control can be used to establish strangeness; control is not always required to establish trust, and so on. To understand these links, the theory of intersectionality helps to reveal the mechanism of identity construction as people mobilise various intersectional identifications that compound their self-identity depending on time, place and context. That is, decisions that are made regarding mobilisation of intersectional identities are at the centre of this chapter.

In addition, this chapter reviews the choice to mobilize forward and perform an intersectional identity. As mentioned in Chapters 5 and 6, becoming stigmatised and “othered” can problematize belonging and strangeness negotiation, hence also interrupt the intersectional process. Questions of visibility of health disruption, for example, demonstrate the intersectional possibilities individuals have about whether disclosing their physical condition or not.

This chapter reviews the ways the participants in this study activated their agency in regards to choosing the different elements of control, trust, belonging, strangeness and intersectionality. The different links between these concepts are multiple and will be demonstrated based on the choices that the participants made during previous interactions, as provided by their narratives.

Choice of Control, Trust and Intersectionality

Choice impacts individuals’ construction of interpretations, which in turn impact construction of trust and control. It is true that interpretations are constructed based on cultural models and other societal conventions, and yet social actors are also active agents who hold subjective perceptions and views. The term choice has been chosen deliberately as it holds a moral value that stands for individuals’ agency and responsibility of self-identity construction. Within this intersectional process there is always a choice
of how to execute one’s agency and how to reach optimal levels of trust and control, even if these are impacted by social structures. In addition, choice is a relevant notion in many aspects as health disruptions undermine opportunities for identity and belonging/strangeness construction and performance.

This chapter unpacks this dynamic process by examining how choice is powerfully intertwined with intersectional considerations through drawing on the participant narratives. This then helps to deepen understandings of belonging and strangeness negotiation, particularly following identity reconstruction in the wake of biographical disruption. Ultimately, this chapter and the previous two provide a basis to then present the CSC model in the final chapter, which draws the links between control, safety, choice, intersectionality, belonging–strangeness, and self-identity construction.

**Intersectionality of Belonging and Strangeness Construction**

Intersectionality theory suggests an applicable framework which focuses on the way in which different social categories (gender, race, etc.) affect particular social behaviours or the distribution of resources (Yuval-Davis, 2011a). However, intersectionality extends beyond power dynamics by acknowledging that identities are context-dependent. This perspective allows for a deeper comprehension of how social behaviors and resource distribution are shaped not solely by power dynamics but also by the particular context in which they unfold. One’s intersectional identity relates to notions of belonging as well as strangeness. In other words, once an intersectional identity is performed (that is, mobilised forward) in a particular context, the potential to belong should be examined, along with the potential to not-belong (that is, to become a stranger). For example, according to Anthias (2008), a drastic change of life does not necessarily lead to all intersectional identities to develop strangeness towards others. As social actors have a variety of intersectional identities, they may negotiate belonging based on their class or gender identities, if other intersectional identities would evoke strangeness with others. This means that even the most radical experience of estrangement will not necessarily eliminate one’s ability to construct a sense of belonging through other social categories. On the other hand, it also suggests that no “pure” belonging can be constructed, as some intersectional identities may differentiate a person from another individual or collective with whom s/he is affiliated.

An interesting choice made during times of change is between intersectional identities as part of a belonging negotiation process. Intersectional theorists, according to Nash (2008), should not only describe the intersectional process but also ask what determines its design, “by which subjects mobilize
(or choose not to mobilize) particular aspects of their identities in particular circumstances” (p. 11). If we take into consideration that health disruptions undermine notions of belonging that have a clear impact on self-identity construction, then the relevance of choice of intersectional identity becomes clear. The last aspect of choice is regarding the narratives provided by the participants: the choice of words and narrative construction and design is a part of a meaning-formation process that is part of self-identity construction, as discussed in Chapter 4.

Social role theory, which was presented by Wolfensberger (1999), considers people’s social roles as a key factor in the process of receiving recognition or being devalued, as social roles can be “viewed as a combination of behaviours, functions, relationships, privileges, duties, and responsibilities” (Wolfensberger, 2000, p. 110) and thereby impact the intersectional process, as the following narrative demonstrates:

Ben: When they were kids, I remember one time we were at an underground parking lot, and I got out of the car, and my younger son started running in the lot, at the time he was 4 and I couldn’t chase him. And his older sister, only 6 years old back then, shouts at him—“Stop! We’re going to walk at Dad’s pace.” On the one hand you want to smoosh her because she is so amazing and adorable, but on the other hand you want to cry. Why should a 6-year-old have to deal with her dad’s condition? Having an awareness is great, but why does she, at such a young age, have to deal with it? It has its upsides and downsides. Luckily, I had the opportunity to be active with them before it was too late. We went on vacations, on each annual leave from work we used to travel together to Eilat, each time to a different hotel, so we would visit the underwater observatory, or sail a boat and have the chance to do things together before the illness took over. Within the boundaries of my physical limitations of course. You can’t go diving with a wheelchair. But if they would ask me to go diving then I would find a way.

People have many different social roles that help them to construct their social boundaries and belonging: people can have family roles, marital roles, professional roles, community roles (citizen, community activist, voter etc.), religious roles, age roles and so on. Like intersectional identity, the number and component of roles is unlimited and singular (Yuval-Davis, 2006). Social roles, according to Wolfensberger (2000), affect “just about every aspect [of people’s] lives” (p. 111) as they determine what relationships people are allowed to develop, and with whom. They impact where people are allowed to live, what activities they will do during the day, what their economic status will be, what
degree of respect they will receive from others and much more. According to Wolfensberger, people with disabilities (that is, experience health disruptions) are devalued and excluded from many highly valued social roles that provide people who hold them with high status and recognition. People who experience health disruptions are usually positioned in low-income jobs as a result of this experience (Wolfensberger, 1998), and in other times may not be allowed to start a family (especially when intellectual disability is the case).

In fact, Wolfensberger (2000) uses an intersectionality approach and charges it with social values: people are not only Black, mothers, managers or having health disruptions, but are also performing social roles that have different values in social contexts. Having a low-status social role, as health disruptions may cause, devalues people and “wounds” them.

For instance, the value that is charged to Ben’s role as a father allows him to develop self-esteem along with a sense of belonging. He does not only feel that he is valued as a father but also mentions the ways his children help him to establish a sense of belonging when they wait for him in the parking lot so they can all “walk” at the same pace. However, it should be noted that a new social role that his daughter is performing may undermine his social role as a father. Therefore, the second part of his narrative is utilised to reestablish his identity as a competent father (But if they would ask me to go diving then I would find a way). The way to heal the mentioned wounds, according to Wolfensberger (2000), is to charge these roles with a high value, and this idea is, of course, at the heart of the social and affirmative models of disability. As such, Ben utilises his agency to overcome potential strangeness that society may impose on him as a result of MS. He describes his intersectional identity as a father with minimum interruptions as possible, and adds to it self-awareness that is appreciated within this role. In other words, he can establish aspects of his belonging (to his family and to able-bodied society) based on his role as a father.

Another dimension of belonging construction is related directly to intersectional identities, and not only to social roles that intersectional identities are linked to. When one’s intersectional identity is not acknowledged by others then construction of belonging may be undermined, as the next narrative demonstrates:

  Maya: I think my mom didn’t realise just how much I couldn’t see. She didn’t realise. If she knew then she wouldn’t have told me, after she lost vision in one of her eyes, that if Moshe Dayan [a former head of Israel’s defence force who wore an eye-patch] could manage with one eye, then
so could she. That hurt me so much. I'm right next to you! Your daughter who can’t see! And I was sitting next to her, and she knew I couldn’t see, but wasn’t aware of it. Because I’m so independent, no one ever believes I can’t see. Not long ago, I got in a taxi, with a driver I’ve known for a while now, I folded my white cane and he said, “I see you manage so well, why would you need a cane for blind people?” So, I told him, “Because I can’t see”—“You can’t see?” People don’t believe it.

An effort by Maya, who has been near-sighted for years, to manage her health disruption was not acknowledged by her mother. In other words, an intersectional identity that represents achievement and overcoming challenges was not acknowledged by a significant person in Maya’s life, and her frustration is clear: from an intersectional perspective she chooses to mobilise an intersectional identity that is related to a health disruption, and by doing so is demonstrating a rather different choice regarding this identity mobilisation than other participants in the research. This is because Maya mobilises her intersectional identity that is related to her health disruption forwards within this narrative and aims to incorporate it into her self-identity; and is doing so by its acknowledgement by others. However, her mother did not provide her the desired feedback, and a potential for strangeness between mother and daughter is then evoked. To prevent construction of strangeness with her mother Maya explains that her reaction was common—her mother was only one of many people who did not believe Maya had a visual impairment. In other words, she designed her agency to silence an intersectional identity that is related to a health disruption, and as a result is able to prevent of belonging with her mother being undermined.

This is an execution of primary control, but in fact her narrative is designed in a way that aims to neutralise potential principal strangeness between daughter and mother. Her narrative reflects a delicate dynamic that is related to intersectionality: people should not be narrowed to one intersectional identity (health disruption, religion, race, and ethnicity, for example) as this may lead to objectification of the self (hence, strangeness); at the same time, they should feel safe knowing that all their intersectional identities are valued and appreciated in the right context, and as a result belonging construction is available. It is important to mention that there are different ways to acknowledge intersectional identities, or people’s achievements that are related to them. Ella’s narrative, for example, presents a more complex approach:
Ella: I was not always my sister’s role model, but suddenly we switched places. I didn’t have any money, couldn’t find myself, while my sister got a job. Then suddenly I found something that gave me a reason to live, and since then it doesn’t matter at all what anyone thinks of me. I have my centre, and others still affect me, but not as much. My family, that is. They affect me less because they hardly know what I actually do. As a matter of fact, my friends, teachers, and mentors have a much greater effect on me. But my family has less of an effect on me... I know they’re still there for me. They want me to be happy and they worked hard for that. And I will always remember that, I was hospitalised for years and they were with me. No one else did... so I cherish that, I know they are my space of relief, a place where I can take a rest.... And I did tell them I was sad that no one from my family bothered to wish me good luck with my exhibition, and that was very hard. Actually, I have a friend who said “If they don’t bother you, if they’re not even wishing you good luck, then that means you’re doing okay.” Because they don’t interfere. No matter what, they don’t interfere. I don’t invite them to exhibitions, either. I let them know when there’s an opening, but I don’t want them to come. They wouldn’t know what to do in that space full of photos. They come all the way from Golan Heights to Tel Aviv for 5 minutes and then go back. It’s a waste of time.

Intersectional identity as an artist provides a centre that means Ella doesn’t need to consider what other people think of her. This intersectionality provides her a centre of stability, as well as a sense of belonging that her friends, teachers and mentors provide. A sense of belonging to one social arena (art) can impact the level of strangeness towards another arena (family), or at least be utilised to shape the level of available strangeness: her family does not know much about her work, but still provides a safe sphere, a place where Ella can “take a rest.” It is not that Ella does not trust her family, on the contrary, she emphasises that they were the only ones who helped her during times of hospitalisation, but an intersectional identity that is related to her professional identity allows her to put more trust in others than in her family in particular contexts. This is not a case of distrust, but rather an example of the way in which intersectionality affects trust construction, as it could be claimed that Ella understands who can and who cannot carry the obligations and responsibility that she needs (Sztompka, 2000) to construct her intersectional identity as an artist. She does not expect her family to develop a professional knowledge about her work, and does not resent them for that. She prefers not to challenge them and not ask them to visit her exhibitions. Rather, she uses her agency to compartmentalise sections of her life to build relevant trusted networks that support different intersectional identities. Lastly, by asking
her family not to attend her exhibition openings she allows herself to impact the interaction and establishes a sense of control.

This demonstrates, in contrast to the narrative provided by Maya, that a full acknowledgement of an intersectional identity and understanding of its components are not always necessary. Ella feels she is part of her family, and can rely on them despite the fact that they do not have much knowledge about her work, which is a substantial part of her self-identity. By doing so she can frame a mental space of safety that positions her and her family in an optimal belonging location. Her narrative demonstrates that intersectional identities enable the construction of distinctive circles of belonging that in return allow the construction of these identities. Undermining of belonging after a health disruption takes place will therefore put one’s intersectional identity construction at risk, as well as notions of control and safety.

People construct their identities in a direct link to the potential to establish belonging; however, there are more ways to construct, or manifest, intersectionality in the social world. One of them is related to representation of intersectionality by other individuals. Ben, for example, refers to his caregiver and the way he was accepted by Ben’s close friends by answering my question: *did it influence your relationship with your friends?*

*Ben: He was accepted into the group. He arrived, introduced himself to everyone, he became, I can’t say we treat him like family, but we treat him as one of us.*

*Shira: What if they didn’t accept him?*

*Ben: No, I would, I would confront them. He is here to help me, it’s not like I brought him along because he was bored. He came here because I needed his help, and instead of asking for their help—not that I ever asked for too much—but with some things, after some time you realise that he is able to do them and it helps me. He makes my life easier, I’m not as tired as I used to be, I exert myself less.*

*Shira: Accepting him actually means accepting part of your own life?*

*Ben: Yes... It’s not like I ever gave them notice, like “Today I’ll be arriving with my caretaker.” I just went there. “Meet Tamesh, my caretaker, assistant, or whatever you want to call it,” and
Ben’s caregiver, Tamesh, is obviously linked to Ben’s MS, therefore accepting him is supporting Ben’s changing physical needs. On the one hand his friends are inclusive towards the MS, but if they were not then Ben could confront them. He can do so as he is an equal member who belongs to the group. His narrative signals his belonging to a group that shares values and norms; therefore, his ability to confront can also represent his agency to apply social control over his friends, and form a type of control that assumes people can choose their behaviour and do so by utilising shared values, goals, etc. (Das & Teng, 1998), hence by construction of a sense of belonging. In other words, as part of the group Ben shares norms of inclusion that could be used as the conceptual justification for confronting his friends. As social control acknowledges people’s agency to make decisions (Das & Teng, 1998) then it should be assumed that potential confrontation would not be effective without notions of trust between Ben and his friends. Therefore, Ben reaffirms his belonging by utilising his agency within a social control framework, and his friends reaffirm his belonging by constructing belonging with Tamesh who represents an intersectional identity that is related to Ben’s health disruption.

The last point refers to Tamesh’s belonging: as a caregiver he can negotiate his belonging to the group by relying on the value of his social role that supports one of the group members. This narrative, in fact, portrays a moment in Tamesh’s own acculturation journey in a new country, that kindly reminds us that in any given interaction there are numerous social actors who are engaged in negotiation of belonging and strangeness.

**Choice and Intersectionality**

So far belonging and strangeness have been reviewed through lenses of intersectionality and divisions. However, my main claim is that belonging and strangeness are key motivators during self-identity construction after a health disruption. After such event, at times, the motivation to construct belonging or strangeness could become related to the motivation to construct one’s self-identity as before a health disruption. However, the relevant question remains:

*How do people use their agency to construct belonging/strangeness within the intersectional process?*
The notion of choice can begin the explanation to this question. At this point it should be reemphasised that the participants in this research did not choose to undergo a life-changing experience. As such, it can be assumed that they will be motivated to reconstruct their identity as before in a consecutive way (that is, with as minimal interruption as possible). In the next section, the notion of choice will be examined through the intersectional process in which people construct their belonging/strangeness by utilising trust and/or control. The choices reviewed indicate participants’ interpretation, behaviour and performance, hence agency. The idea is to reach a higher resolution of the intersectional process and see how the motivation to construct belonging/strangeness triggers people to mobilise intersectional identities, and how trust and control activate this process.

It should be reemphasized that not all intersectional categories were unpacked, but mainly those who were mostly relevant to belonging negotiation, thus those that are relevant to family roles. As a pioneer research in terms of seeking for the mechanisms that allow social actors to negotiate belonging and strangeness, it was impossible to ignore intersectional framework, however, within a PhD scope it was not possible to expand the number of intersectional categories. Thereof, the next narratives and their analysis attempt to shed some light and contribute to the understanding of self-identity construction. The analysis cannot grasp all of the intersectional process, and instead aims to trigger new questions and add value to present research.

Sharon: And then I picked up a book, after the week I spent at the hospital, I was at home and had a book about MS.... So I looked at this enormous book, but then my mother’s brother came around to visit me, and he’s a very strong person, he survived cancer and had a good recovery, his life is completely back to normal. And he comes in and sees me with this book, and he says, “Take this book away, it has nothing to do with us. No way! It’s something else completely. Don’t read this nonsense. That’s not about you. Look, everything’s just fine.” And he gave me some perspective. And this is how it went, my whole life, I actually have very strong support from my family. Very strong.

The narrative above demonstrates the ways in which social divisions are formulated as a result of the ways individuals subjectively experience their daily lives in terms of inclusion and exclusion; this includes not only how they perceive themselves and their social positioning, but also their attitudes and prejudices towards others (Yuval-Davis, 2009). The concept of trust, in this case, dictates what Sharon considers as part of her identity and what is not. She describes a very strong family support that led to
construction of clear boundaries between what “belongs” to the family and what does not. As a result, during a particular interaction, she rejects the cultural object that stands for MS and does not incorporate it into her identity at that moment, on the basis of the trust she holds in her uncle. Her agency is utilised to construct belonging through trust, as a means to reject an intersectional identity that is related to her health disruption, and prevent identity interference. Sharon establishes the trust she holds in her uncle within the narrative she constructs, to support her choice: “he is a strong person, he survived cancer and had a good recovery, his life is completely back to normal”—her uncle’s physical (and/or emotional) abilities are used as a justification since he went through a similar experience to hers (survived a life-threatening illness), and has survived it, hence holds the ability to cope with a similar situation and understand what Sharon is going through. He is not only a competent trustworthy person, but also one who belongs to the “normal” world.

The book about MS could provide Sharon with information about her condition, and as mentioned before, information can lead to development of interpretive control (Rothbaum et al., 1982); however, it may also lead to the understanding that the situation is not controllable (Rothbaum et al., 1982) and may have a negative effect on Sharon’s well-being. This may be the problematic result that her uncle identifies as he instructs her to reject the book that stands for an intersectional identity that is related to health disruption (as well as for the concept of control). Again, the narrative revolves around the choice of keeping the familiar and what is perceived as safe; however, it also demonstrates a particular interaction that indicates how belonging affects intersectionality processes during life transitions.

Circles of trust include individuals who are familiar to us and those with whom we have things in common. The quality of trust we have towards different people reflects the sense of belonging that can be constructed within these relationships. As mentioned in the previous chapter, what Sztompka (2000) defines as the tension between trust and distrust can be considered as the tension between belonging and strangeness. We belong to those (and what) we trust. Sharon’s belonging negotiation process allows her to construct strangeness towards her health disruption. It enables her to consolidate her own link to MS and its impacts on other intersectional identities (at this early stage of the illness development).

This demonstrates Möllering’s (2013) claim that “trustee and trustor keep on constructing their identities together in the process of trusting” (p. 294), which was mentioned in the previous chapter. During this interaction, Sharon is constructing her identity regarding MS and other intersectional
identities, along with a choice to trust that indicates and confirms her willingness to belong to her family. In fact, as mentioned earlier, trusting others signals and confirms people’s aspiration to belong to individuals or collectives (Möllering, 2013). Trust assists with maintaining in-group forms of identification as a basis for positive expectations between group members, thus trust builds on and sustains personal and collective identities (Möllering, 2013).

Another way to establish belonging can be to charge intersectionality with a new meaning:

Sharon: She makes me laugh, my sister, she’s amazing. She has this laughter and she is... she makes everyone around her happy, they always laugh. She has this sense of humour, she’s very sarcastic... so she’s... I love being with her. And she’s been with me through the worst of times, actually they all, my whole family, because we have this connection... It reached a point when she had to take me to the MRI at 4 in the morning, and I was in a wheelchair, because it was quite a long way from the parking lot. We got to the hospital and she pushed me, in the wheelchair, and ran like this (laughing) pushing the chair, it was so funny. She helped me during those times, helping me wash, I couldn’t... my old flat had a bath and I couldn’t stand up, so she would hold me up like that, lift me up and pull me out. All sorts of things... we went through a lot together. Do you know what she did after the MRI? She took me to the mall and we got our nails done, because I needed a manicure, and that’s the sort of fun atmosphere that she created, like everything is going to be okay. Everything was positive.

This example demonstrates not only an inclusion and support of a marginalised intersectional identity by Sharon’s sister, but also a process of charging it with a new meaning—running and pushing her sister who is sitting in a wheelchair in the hospital’s corridor means elevating an intersectionality into a different context; taking her sister for a manicure after an MRI scan means Sharon’s sister was able to trigger a new engagement of this intersectionality to her daily life.

First and foremost, an inclusiveness of an intersectional identity that is related to a health disruption allows trust to be built between the two sisters, as Sharon can rely on her younger sister to take her to the hospital in the middle of the night, and later provided the conditions for a temporary suspension of regular cultural constraints and conventions (Sztompka, 2000)—which operate within a mental sphere that allows elaboration of agency, of nonconformity and freedom of action. As mentioned before, when trust and control are established, then belonging can be constructed; together, the two sisters are able to share optimism that may rely on their ability to impact the negative outcomes MS has on Sharon’s
identity: by going for the manicure after the MRI, they have proved to themselves that the MS did not make them helpless, as they were able to rise above its implications.

Therefore, it should be asked—how can social actors’ agency impact intersectional processes? One claim could be that interpretation of events, interactions with others and self-identity construction are the domains in which individuals’ agency is activated.

Daniel: And years went by, and around the age of 23 my darling mother had raised the proverbial question, and asked me to tell her why I didn’t have a girlfriend in so long, and could it be possible that I was gay. And I was a bit surprised with the question, because the time and place were odd, it was right before Friday dinner at my grandparents’ house, in the kitchen, and I was like, okay, that’s not the best timing. But I told myself now was the moment I had to, and this was one of the only manly moments in my life, I told myself I had to make a decision on how to answer this very direct question, because it was clear that behind this question stood an exclamation mark, and I didn’t want to weasel my way out of it, but I also knew that coming out as gay would raise a lot of antagonism… but I made the choice to be direct and I answered yes, and then all at once I saw my mother’s features collapse and a great sadness gradually falling over her, and I looked at her, and firmly told her, “Listen, if this is going to be our main issue now, then you should know you just lost your son. As far as you’re concerned, I just told you I preferred the color blue rather than red, and it doesn’t matter because it’s just another preference that I have in life, it shouldn’t affect you and it shouldn’t take anything away from our relationship, and if you’re going to turn this into the main issue of our relationship then you should know that you’ve just lost me.” And that was that. I mean she did go to the other room and cry, and I didn’t follow her to pat her on the head and tell her everything will be okay. On the contrary, I let her wallow in it. She wanted to wallow, so I let her do whatever she wanted. I said what I said and that was that. That was my coming out.

The situation described here is about another intersectionality and refers to Daniel’s sexual identity, and his coming out to his mother. This experience is not necessarily related to Daniel’s biographical disruption; however, it is interesting to examine how an interaction with potential for strangeness development is constructing Daniel’s agency to establish control to manage his belonging. In terms of control and trust, it can be said that the situation represented two problems for Daniel: the timing and location of the conversation was odd (it was right before Friday dinner at my grandparent’s house, in the
kitchen) thereby it can be assumed he was caught off guard and was not prepared for his mother’s question (hence his notion of control was undermined). On the other hand, Daniel knew that the information he was going to deliver about his sexual identity “would raise a lot of antagonism.” Furthermore, his narrative indicates that he knew there was a potential for his mother to gain control, hence loss of control for him, as “it was clear that behind this question stood on an exclamation mark.” Moreover, this exclamation mark may represent potential strangeness that could be imposed on him by his mother since his sexual identity is different than she expected and is stigmatised. This introduction comes to explain his reply strategy as he states that a conscious decision to charge his intersectionality with a new meaning: “As far as you’re concerned, I just told you I prefer blue rather than red.” He drains his sexual identity from its meaning and charges it with a neutral one that should not indicate his belonging to any community.

Daniel is also requesting not to be narrowed to one intersectional identity: “and it doesn’t matter because it’s just another preference that I have in life”; however, he does not ask his mother to be inclusive towards it; on the contrary—he provides her specific instructions of how to relate to his intersectionality: “it shouldn’t affect you and it shouldn’t take anything away from our relationship.” He opens this part of the narrative and ends it with a clear ultimatum that compensates for his sense of loss of control: if his mother does not obey his instructions then she should know that she was the one who brought misery upon herself (you should know you just lost your son).

Hence, the strangeness that may be imposed on him is now used by him and is directed towards his mother. Ironically, he gains control by directing all the responsibility for their relationship at his mother, that if she is unable to follow his orders then she would be responsible for the loss of their relationship. Having said that, it seems that Daniel’s scope of choice is more limited when it comes to his intersectional identity that is related to hydrocephalus:

Daniel: But my illness is more substantial, because it has an immediate effect on my daily life, it is not an intangible concept, that could also be translated in her thoughts to—you will never have a family, you’ll end up lonely for the rest of your life, you wouldn’t have a wife to support you and care for you and cook for you and make for you; and how long will I have to take care of you? Not that I ever asked her to do that. But I do understand the long-term perspective she has about this issue. The illness, however, has relevance in my daily life... but I know that there is always the option that I would have to rely on them.
Not all intersectional identities can be charged with new meanings in all contexts. However, the impact individuals can make even within objective limitations is meaningful. They do so by utilising notions of control and trust that directly impact belonging and strangeness negotiation and impact self-identity construction. The narratives reviewed so far revolve around different constructions of intersectional identities and all reflect belonging and strangeness negotiation. Utilisation of trust, control, and intersectionality demonstrates the agency that social actors choose to execute when operating in the social world and constructing their self-identity. This is particularly true for a dynamic that characterises the experience of health disruption, however, it could also be relevant for any life-changing event in individuals’ lives.

**Summary**

Choice of control of trust impact belonging and strangeness renegotiation after a health disruption. The formation of these choices lead to performance of an intersectional identity. The different factors impact each other’s development and eventually shape social actor’s self-identity.

As mentioned before, social actors are active and have agency to shape their interpretation and behave in ways that directly impact their belonging and strangeness negotiation. For example, they are able to form a sense of control when potential for strangeness arises, as Daniel’s narrative demonstrates. Multiple interpretations, and thus actions, design social interaction and belonging and strangeness negotiation. For example, at time it is important that relevant intersectional identities would be acknowledge by others. However, at other contexts it is not a meaningful factor which its absence have a negative impact on belonging negotiation.

Having said that, as mentioned in Chapter 3, individuals do aspire for recognition of their identities by other people as it has an intrinsic value for their self-esteem (Taylor, 1992). Ben’s narrative, for example, demonstrates how his social role as a father provides such value, regardless of his health disruption. This example also indicates how intersectional identities counteract each other in a cultural dynamic that aims to enhance a sense of belonging.

This chapter demonstrated the participants process of belonging and strangeness negotiation, as motivated by their choices. The next chapter will pack some of these ideas in a form of a model that could stand for self-identity construction dynamics that involve choice of control, trust, and an intersectional identity as part of belonging and strangeness negotiation. This should assist with
understanding the complex dynamic between all the concepts that have been discussed so far, and the way they are shaping self-identity construction.
Chapter 8: The CSC Model

Introduction
The multiple relationships that can be maintained amongst the CSC factors (control, safety and choice) are at the basis of this thesis. They relate to humans’ needs during belonging and strangeness negotiation after a health disruption, but can in fact be applied to any self-identity construction, regardless of the type of life transition. These processes involve the intersectional formation and impact individuals’ self-identity construction. Unpacking the mechanism of belonging and strangeness negotiation, then, provides the first map of understanding individuals’ needs during social interactions.

The CSC model allows us to examine self-identity construction through the lenses of belonging and strangeness negotiation. One’s self-identity is always constructed in relation to an individual’s location on a belonging–strangeness continuum that is linked to another person, a group, or a cultural model (an object or a concept). In other words, since self-identity is always constructed in relation to “others”, then focusing on the ways people construct their belonging (and strangeness) allows insight into the mechanisms of self-identity construction.

By utilising the CSC model, I seek to understand the choices people make of intersectional identities while trying to establish trust and/or control in order to negotiate their belonging and strangeness. Their choices, however, do not reflect an absolute freedom (as individuals operate within a cultural structure), and in this sense the usage of the word “choice” may be problematic. However, inspired by the affirmative model of disability, the decision to use this word has a moral value behind it. The choices social actors make always operate within cultural structures that enable them a different, and at times constrained, range of choices. However, out of this range individuals do make decisions about how to activate different CSC factors to negotiate their belonging, strangeness, and self-identity. As mentioned Chapter 2, different models can trigger construction of interpretations of what health disruption is and impact belonging and strangeness negotiation. However, not all model perceptions are manifested in the social world in the same ways. CSC factors have multiple and complex links between them, and since other social actors would impact interactions as well, it is safe to say that the element of choice continuously operated and is linked to individuals’ agency when it comes to interpretations they make and self-identity construction.
When constructing categories of belonging, as mentioned in Chapter 3, categories of strangeness are usually constructed as well. Both strangeness and belonging have a number of dimensions: while belonging is linked to the potential for constructing affiliations with other individuals or collectives that share similar social locations (people’s gender, class, race, nationality etc.), strangeness can trigger the acknowledgement of a difference between these same categories, but does not necessarily lead to hostility or detachment.

The objective of the CSC model is to review the conditions that can be related to negotiation of belonging and strangeness in variety of contexts. Not only should external conditions or feedbacks be taken into consideration during belonging and/or strangeness construction, but also internal processes that people activate to generate meanings that inform their behaviour during interactions. This means that misinterpretations, relying on familiar schemas, or development of new meanings should also be explored within the model’s scope. For example, the model claims that in order to fulfil oneself as a subject, one must have (at least the illusion of) a free choice within the limits of a particular interaction. Another example is the concept of “perceived control” which demonstrates the needs that exist and are satisfied within one’s mental sphere. Another condition for belonging construction, at times, is recognition of all intersectional identities by the other. If an intersectional identity is not acknowledged in specific contexts, then a sense of alienation and strangeness may be constructed. However, in other contexts it seems that acknowledging intersectionality may disrupt belonging negotiation, as in the case of an invisible health disruption. Therefore, the CSC model cannot be utilised without taking into full consideration the context of a particular interaction between social actors. In some cases, for example, individuals can be reduced to one intersectional identity as they are denied opportunities of choice, control and trust, thus a potential for strangeness towards the other may be established. Recognition of intersectional identities can be recognition of another person that is related to that identity, or an object, behaviour, idea, etc. However, others’ recognition of intersectional identities is complicated and has many layers as different needs that are linked to an intersectional identity should be fulfilled within the dynamic of interactions with others, as discussed in the previous chapters.

The core of the CSC model is the notion of choice that is implied in three levels:

1. Do social actors choose to construct trust and/or control, and what meaning are they charged with?
2. What intersectional identity is chosen to be mobilised forward and what meaning is constructed for it by social actors?
3. In what way are the two processes above utilised to construct belonging and/or strangeness?

The CSC model
As presented in Chapter 1, the CSC model offers the following process in relation to self-identity construction (Figure 1).

Figure 1
The CSC Model

![The CSC Model Diagram]

However, to understand the role of CSC factors, the model has been divided, in Figure 2, into three levels: CSC factors dynamic, the CSC model on belonging–strangeness continuum, and multiple interactions that involve CSC factors that accumulate as what is defined as “self-identity.” The additional unpacking of the model’s layers is provided for a better understanding of the concepts and the relationships between them, as well as stimulation of the potential for additional links that may be constructed between CSC factors.
CSC Factors

Safety and Control. As mentioned earlier in this chapter, the three main factors of the model are safety, control and choice—which operate in an interlink to intersectionality. The previous chapters (in particular 5, 6, and 7) demonstrated how the construction of each factor can impact the construction of other CSC factors, as well as intersectionality.

Figure 2

CSC Factors Dynamic

Control is examined within the CSC model through the notion of perceived control, as the focus is on one’s sense of establishing or lacking control. Although control is at most times an illusion, people still strive to gain a sense of it when negotiating their belonging and/or strangeness, particularly after a health disruption. As such, the undermining of one’s sense of control can have a direct impact on self-identity construction. People’s agency is represented not only by primary control but also secondary control. When belonging construction is undermined and primary control is not possible, individuals usually choose to apply secondary control as a means for belonging construction. Secondary control has a great impact on notions of belonging and strangeness construction as social actors generate different meanings: people may be inclined to construct control to promote a sense of vicarious control that is based on belonging construction, or withdraw from potential interactions as a mechanism of defense against disappointment and a construction of strangeness, and thus will be inclined to negotiate strangeness. These ways, for example, are utilised by the participants to renegotiate their belonging and strangeness to manage a stigmatised intersectional identity.

The CSC model also examines the concept of safety—which is divided into notions of home and trust—and its direct impact on belonging/strangeness construction. Home represents the spatial aspect of
safety, and can function as a meeting point for safety and control, as home represents a sphere that is under one’s control, as mentioned in Chapter 6. The physical and symbolic recodification of a familiar space (or the way social actors operated within them before health disruption) stands for the disruption in control, trust and, at times, choice. Mental displacement can also stand for the disruption people experience in relation to belonging construction, hence self-identity construction. A new home, for example, will be constructed in reference to the original home, and in it, one will always lean on familiar schemas that provide control, to ensure a notion of feeling at home. Lastly, home always has some link to the other: it is constructed and charged with meaning in relation to cultural, psychological and social dispositions that are intertwined in a process of belonging (and strangeness) construction. The idea of the gaze, for example, has been examined at Chapter 6 as a metaphor of this aspect, and led to the understanding that choice is a factor that impacts an individual’s ability to establish a sense of feeling at home in regard to how much to let others “into” the conceptualised home that stands for one’s self-identity.

Trust represents the social aspect of safety, since its establishment through interactions allows the potential for belonging construction. Trust circles overlap belonging circles; that is, we trust those with whom we belong. Principal trust, for example, can exist in one circle of belonging but not in another. Having said that, at times belonging construction in one circle impacts another: Ben, for example (as recounted in Chapter 6), suggests his daughter follow an inclusive approach when interacting with others, even if they are strangers.

As stated before, the model is interested in narratives and interactions that are engaged in self-identity construction, and thus suggests that self-identity is constantly constructed in relation to changing dispositions of belonging and strangeness that are parallel to the trust–distrust dynamic. Factors like risk, in addition, can affect trust construction. Risk is not only related to the notion of control and trust, but also impacts notion of choices that social actors employ during belonging and strangeness negotiation.

Trust and control are two main factors that impact belonging and/or strangeness construction. The two do not have to be constructed simultaneously, or in any particular order, to provoke belonging or strangeness construction. Both control and trust assume the existence of the other; however, they do not always impact each other. At times trust functions as an opposite of control; that is, trust is related to belonging, and control to strangeness. In other situations, they maintain a complicated relationship in
which the construction of one leads to the construction of the other; in other words, they are continuous. For example, people’s agency to establish trust can be transformed into primary control behaviour that can positively impact the development of belonging. Lastly, since the links between control and trust are fluid and contextual, control cannot be a complete substitute for trust, as it may be harmful and lead to negative implications that will impact people’s social relationships and sense of self, and could even lead to paranoid behaviour.

**Choice of Intersectional Identities**

As mentioned at the beginning of this chapter, the model has focused also on the choices that individuals make during intersectional processes that are related to health disruptions. Notions of intersectionality were examined when different identities were mobilised forward and when they were silenced. At times the performance of an intersectional identity came to prevent strangeness construction, at other times it was utilised to actively construct belonging or strangeness: for example, when a social actor chooses to mobilise forward an intersectional identity they have in common with another person it may lead to trust development and belonging construction; When Sharon rejected a book about MS because her uncle told her to do so, her motivation was to construct belonging with a family member. To do so she mobilized an intersectional identity that was related to her familial role as a niece, rather than an intersectional identity that is related to MS. The model also revolves around choices that are related to charging intersectionality with a new meaning, as Daniel’s coming out narrative demonstrated (*I just told you I preferred the colour blue rather than red*, recounted in Chapter 7).

**Belonging–Strangeness Continuum.** The choice of an intersectional identity mobilisation, along with choices that are relevant to safety and control, reflects the process of identity construction. The model as presented in Figure 4 represents this process.
The model shows how choice is involved in the process of safety, control and intersectional identity. The choices made by social actors help to inform the way each of the factors is constructed and impacts belonging and strangeness positioning on a scale that is relevant to a particular context. To be more specific, social actors would construct acceptance or rejection of different cultural models, social actors, and intersectional identities and thereby would impact belonging and strangeness negotiation. Not only original schemas involved in the process of belonging negotiation of cultural models and intersectional identities, but also the dynamic that is constructed with other social actors, that may, in fact, impact these schemas and their relevance to an individual’s life, as discussed in the case of stigma for instance.

The above components interlink in different ways within multiple interactions on a belonging–strangeness axis that impacts self-identity construction. For example, an interaction that would have the potential to construct belonging with others can be presented as in Figure 4.
However, interactions that have the potential to construct strangeness would appear as in Figure 5.

**Figure 5**
*Interactions With the Potential to Construct Strangeness*

Control and safety, along with one’s selected intersectional identity, are interlinked and manifested by an individual’s agency. The model demonstrates that there is a link between a sense of control and safety and individuals’ choice to mobilise different intersectional identities. This process takes place on a belonging–strangeness axis, and the multiple interactions and interpretations that are constructed during these processes will eventually be accumulated as individuals’ “self-identity.” Although the model includes wide concepts with a variety of relationships between them, this thesis provides a solid base for
understanding the relevance of the model’s main concepts and the relationships between them, to the self-identity construction process.

**Multiple Interactions Accumulate to Self-Identity.** As mentioned above, the model suggests that there are different choices that can be taken in regard to construction of each component. These countless interactions are accumulated into what is defined as self-identity. The bottom part of the model (Figure 6) unsuccessfully represents such accumulation of numerous interactions in individuals’ lives. Therefore, a second version of this idea is suggested in Figure 7.

**Figure 6**  
*Multiple Interactions That Involve CSC Factors Accumulate to Self-Identity*

![Diagram](image)

Self-Identity

Figure 6 indicates a sequence between belonging and strangeness, in which one’s self-identity is continuously constructed. However, this figure shows only the sequence in which self-identity is being
negotiated, and does not illustrates the multiple interactions and interpretive processes that accumulate into what is defined as “self-identity”. Therefore, figure 7 is offered.

**Figure 7**

*Multiple Interactions That Involve CSC Factors Accumulate to Self-Identity (Second Version)*

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**Self-Identity**

The accumulation of interactions, as well as the interpretations of social actors about these events, can be accumulated into what is perceived by individuals as their “self-identity.” It is constructed in the mental sphere of social actors, which does not always have to have an objective grasp in reality. However, individuals construct their interpretations, as well as CSC factors, according to their needs during belonging and strangeness negotiation, which can be dramatically affected by a life-changing event.

**Application of the CSC Model**

Having devoted previous chapters to detailing the individual elements of the model, and how they are manifested in the narratives of participants, it remains to show how these are synthesised. As such, I would like to present one narrative which will demonstrate the usage of the model for understanding self-identity construction by applying CSC components:
Ella: When you meet a person with arthritis it’s really great, because the pain is unexplainable and then you meet a person who experiences it. By the way, it’s mostly women, I think, but men as well. And when you meet that person so you’re like, you can identify that you both need to talk about it, speaking of community... there’s a group of women, somebody opened this group, it’s a Facebook group, because she realised people have no awareness of this illness, this thing, and women are not aware, even girls as young as 4 can develop this illness, so in the past they didn’t know much about it, and she has arthritis and... then I went scrolling their Facebook page, but I don’t do that anymore, there is great victimisation there and it’s very far from who I am. I feel I’m not there. I’m not part of this community but I do relate to it. I am willing to relate to it but I do not accept the victimisation. How do I relate to it? I decided not to be like them. I will not accept the victimisation. There is something there I will not accept and that is why I relate to it, which leads me to behave the opposite of them. It’s like I say, I am not a victim, my pain can elevate above itself, above this victimisation. And that helps me.

Ella identifies her need to construct an intersectional identity that is related to her arthritis during interactions that involve people who may have experienced a similar pain. The trust Ella is able to establish with a community of people with arthritis is based on the fact that they both are familiar with the impacts of health disruption. The potential for belonging is based on mutual needs to communicate their experience with each other (you can identify that you both need to talk about it). Another option for trust construction is based on an intersectional identity of Ella as a woman, since most people with arthritis are women as well and the similarity in intersectional categories may provoke belonging construction. However, such belonging construction is not possible, according to Ella, as “there is great victimisation there and it’s very far from who I am.” That is, she positions herself far away from this group, hence she locates herself as a stranger on a belonging–strangeness continuum in relation to them. She chooses to not accept an intersectionality (that she interprets) as victim as part of her self-identity, hence activates a primary control. Moreover, she is able to establish a sense of control by defining herself as “the opposite of them” and constructs an intersectional identity that is related to a health disruption but not as a victim, as her “pain can elevate above itself.” This example demonstrates the dynamic of choice in relation to trust and control, the choice of meaning development regarding an intersectional identity that is related to a health disruption and involves a notion of victimisation, and construction of strangeness as a result of the process. Such analyses can be applied to narratives that reflect people’s behaviours, interpretations and meaning development. Because narratives reflect an
ongoing identity construction process, as they include construction of interpretations that impact self-identity, it is be possible to claim that people do not provide contradictory narratives when describing themselves and their lives, but rather compose a multilayered description of self-identity construction. For example, they are able to develop some level of trust towards others while constructing strangeness towards them at the same time. People use narratives to reconcile the contradictions in their lives, and hence provide a complex picture of their self-identity. I constructed the CSC model to identify this particular dynamic by exposing the usage of relevant components like intersectional identities, safety and control. By doing so I hope to focus on people’s agency and the way it is utilised to design their self-identity construction during acculturation processes.

Summary
The CSC model provides a useful framework for understanding self-identity construction processes. It does so by focusing on belonging and strangeness negotiation processes that involve formation of sense of control and trust, and particularly on the intersectional identities that are performed during such social interactions. Belonging and strangeness maybe dichotomies terms, however the sense that is negotiated is set on an axis, as a there is rarely a complete belonging nor strangeness. This could imply that belonging and strangeness are intertwined.

CSC model reflects processes that take place during a drastic life transition, such as health disruptions, however it may be applicable to other contexts as well. Future research may attempt to apply the CSC model on new contexts of life changing events.
Chapter 9: Conclusion

This research has delved into the intricate processes of self-identity construction, with a particular focus on the concept of biographical disruption that stemmed from a health disruption. This phenomenon, marked by significant life-changing events, serves as a crucial lens through which individuals negotiate their sense of belonging and strangeness, all within the intricate framework of intersectional identities.

The insights gleaned from participants' experiences have illuminated the dynamic interplay between these concepts, highlighting the nuanced strategies employed in the negotiation of belonging and strangeness. Even when confronted with a health disruption, individuals exhibit agency in their quest for control and security within the realms of belonging and strangeness. This research reveals that individuals craft inventive interpretations and behaviors to regain a sense of control and trust, directly influencing the negotiation of belonging and strangeness and, consequently, self-identity construction.

Choice emerges as a pivotal juncture where control, trust, and intersectionality converge. Individuals wield their agency to establish control over intersectional identities, fostering self-value and triggering behaviors that facilitate the construction of belonging and, at times, strangeness. This general dynamic unfolds in a variety of ways, contingent on the interplay of trust and control within the realm of intersectional identities and the choices individuals make.

During biographical disruption, people's choices significantly impact their negotiation of belonging/strangeness and self-identity construction. When control becomes the dominant component influencing interactions with others, individuals may risk strangeness. In contrast, when trust in various belonging circles can be established and balanced with control, belonging becomes available. Individuals navigating biographical disruption undergo a process in which they strive to restore their disrupted sense of belonging, achieving this through a careful balance of trust and control and the choices they make regarding the mobilization of intersectional identities. This process, though simple in principle, underscores the complexity and unpredictability of human behavior, particularly in the micro-level interactions explored in this study.

To encapsulate these ideas, the Control-Safety-Choice (CSC) model has been developed, offering a dynamic framework that explores the interplay between control, safety, and choice along the axis of belonging and strangeness. This model elucidates how these dynamics accumulate to shape an individual's self-identity, reflecting the multifaceted nature of self-construction.
Reflections—Limitations and Next Steps

As mentioned in Chapter 1, I was not intellectually obligated to a particular scholar or theoretical framework. As the complicated and rich concepts that were discussed in the previous chapters were all necessary for the explanation of the CSC model, there was a need to free myself conceptually and allow myself to dive into different intellectual “rabbit-holes” that different scholars offered in relevance to the model. Therefore, only after processing the relevant theoretical ideas could they have been analysed and synthesised into this research.

Unfortunately, this thesis can only say so much about all the CSC concepts and the dynamics between them. However, it is clear that a large scope of the model’s potential has yet to be explored and developed, and future research may achieve this goal. Future research, for example, could shed light on other connections between the model’s factors and the way it can be utilised to understand acculturation, biographical disruption and belonging/strangeness negotiation. Further research could also develop the links between CSC factors and explore them in other contexts that could be considered as a type of an acculturation journey.

The participants in this research invested their energy in constructing interpretations that were impacted by the time dimension; that is, the length of time that had passed since a disruptive event. Different interactions take place on a timeline that represents individuals’ life span. As such, they are affected by the distance from events, as well as the interpretations that are constructed. Most of the participants have managed their health disruption for quite some time now, and some have come to terms with it. In addition, most of the participants are over 40 years old, and half are over 60. Thereby, they provide complicated and interesting insights that their lifelong experience affords about how a health disruption impacted their belonging and strangeness negotiation, and as a result, their self-identity construction.

The cultural differences between the pilot study participants and main research participants have not been explored in this thesis. I have submitted myself to their narratives about their lives before and after a health disruption, and did not sufficiently position them within a cultural context that is related to Israel or New Zealand. This is because I did not identify any significant differences in the discourses provided by all participants about health disruption as a general negative attribute. Even when these constructions have been challenged, they were not rooted in a particular cultural context, but always revolved around the participants’ bodies and their physical abilities. Having said that, it was considered
(and reconsidered) whether to incorporate the two pilot study participants’ narratives in the final research. Finally, it was decided that their voices had a crucial contribution to the research development as they led to the question: what are the conditions that are required for belonging and strangeness negotiation? This, in turn, led to the development of the CSC model.

Another criticism that is relevant for this thesis is the intersectional process analysis that is insufficient as it revolves around one main intersectional identity that is related to participants’ health disruption. First of all, such presentation of the intersectional process focuses on the research’s main questions of a new, or renewed, intersectional identity that impacts (and is impacted by) a life-changing event. Secondly, other intersectional identities that have been examined were related to participants’ familial roles (mother, father, son, sister, niece etc.). These were the main identities that were involved in belonging–strangeness negotiation after an intersectional identity related to a health disruption emerged. In addition, the constructionist approach of this research meant focusing on the elements that were identified as most relevant in the participants’ narratives and in their meaning-making, and thereby revolved around the two main identities mentioned.

It could also be claimed that other intersectional identities have not been explored within this research, but future research could do so. However, as discussed in Chapters 3 and 7, intersectionality methodology cannot grasp all intersectional identities of self-identity that are constructed within a particular context. Researchers’ focus will always be inclined to intersectional identities that are relevant to their research questions. Having said that, I urge any reader of this thesis to appreciate it not by what it lacks, but by the potential of the questions it presents.

The most significant criticism of intersectionality analysis, as emphasized throughout this thesis, is that it often shifts its focus away from power relations. Instead, intersectionality approach in this research tends to centre its attention on the agency that individuals wield when navigating their experiences of belonging and strangeness, particularly in the context of significant health disruptions. This shift highlights the notion that intersectionality should not be exclusively examined through the lens of power dynamics, but rather should incorporate a broader perspective that encompasses the multifaceted dimensions of human identity and experience. This criticism underscores the need to move beyond a one-dimensional analysis of power structures and recognize that individuals, even in the face of adversity or marginalization, actively engage in processes of self-identity construction. By placing agency at the forefront, intersectionality can offer a more holistic understanding of how people
negotiate their sense of belonging, manage their strangeness, and construct their self-identities within complex and ever-evolving social landscapes.

In essence, this critique challenges us to expand our conceptual framework, acknowledging that power relations are just one facet of the intricate tapestry of intersectional identities and experiences. It encourages us to explore the dynamic interplay between agency, choice, control, and trust as central components in understanding how individuals navigate their paths of belonging and strangeness, ultimately shaping their self-identity.

Further research aimed at connecting different aspects of intersectionality, including power relations and micro-level investigations demonstrated in the present thesis, could significantly benefit the understanding of self-identity negotiation following life-changing events. By incorporating intracategorical analysis and acknowledging power relations, further research can, for example, illuminate how power dynamics manifest in immediate human interactions across varied contexts. This understanding offers invaluable insights into supporting individuals facing health disruptions. Therefore, further exploration through an intercategorical lens, emphasizing structural power, offer great potential for guiding efforts to better understand and assist individuals experiencing health disruptions.

To conclude, I acknowledge the limitations of the presented study, but claim that the rich narratives that it has collected, alongside a rich review of various literature and multiple scholars, provide fruitful propositions to understand the implications of health disruptions and understanding the CSC model in a range of contexts.
References


[https://doi.org/10.1037/a0014564](https://doi.org/10.1037/a0014564)


Appendices

Appendix A: Initial Ethics Approval

Office of the Vice-Chancellor
Finance, Ethics and Compliance

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

28-Jun-2016

MEMORANDUM TO:
Assoc Prof Jay Marlowe
Counselling, HumServ & SocWk

Re: Application for Ethics Approval (Our Ref. 017447): Approved with comment:
The Committee considered your application for ethics approval for your project entitled Responding to
Biographical Disruption: Navigating Strangeness and Belonging with an Acquired Physical Disability.
Ethics approval was given for a period of three years with the following comment(s):

1) Regarding the invitation letter that you included in your memo, please include the Ethics approval wording at
the bottom of this letter when sending it out. Please also re-check this letter for typos.

The expiry date for this approval is 28-Jun-2019.

If the project changes significantly you are required to re-submit a new application to UAHPEC for further
consideration.

In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is
completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if
you wish to do so. Contact should be made through the UAHPEC Ethics Administrators at
ethics@auckland.ac.nz in the first instance.

All communication with the UAHPEC regarding this application should include this reference number: 017447.

(This is a computer generated letter. No signature required.)
Secretary  
University of Auckland Human Participants Ethics Committee  
c.c. Head of Department / School, Counselling, HumServ & SocWrk  
Dr Allen Bartley  

Additional information:  
1. Should you need to make any changes to the project, write to the Committee giving full details including revised documentation.  
2. Should you require an extension, write to the Committee before the expiry date giving full details along with revised documentation. An extension can be granted for up to three years, after which time you must make a new application.  
3. At the end of three years, or if the project is completed before the expiry, you are requested to advise the Committee of its completion.  
4. Do not forget to fill in the ‘approval wording’ on the Participant Information Sheets and Consent Forms, giving the dates of approval and the reference number, before you send them out to your participants.  
5. Send a copy of this approval letter to the Awards Team at the Research Office if you have obtained funding other than from UniServices. For UniServices contract, send a copy of the approval letter to: Contract Manager, UniServices.  
6. Please note that the Committee may from time to time conduct audits of approved projects to ensure that the research has been carried out according to the approval that was given.
Appendix B: Primary Participant Information Sheet

PRIMARY PARTICIPANT INFORMATION SHEET

Responding to Significant Life Changes: Navigating Strangeness and Belonging with an Acquired Physical Disability

Name of Researcher: Shira Eisenberg
Name of Supervisors: Dr Jay Marlowe  
Dr Allen Bartley

My name is Shira, and I am a PhD student in the University of Auckland, School of Education, Department of Counselling, Human Services and Social Work. I would like to invite you to consider participating in my research project.

The Research Project

I am interested in understanding concepts of “strangeness” and “belonging” after a significant life event, such as acquiring a physical disability. I am also interested in the ways members of their intimate social networks (family and friends) respond to this change. I would like to interview people who have acquired a significant physical disability and learn from them how their life has changed due to the event. In addition, I would like each participant to nominate two people from their close family/friend network who I would interview twice to see how their broader social environment responded to this change.

The research goal is to have better understandings of the ways people with an acquired physical disability renegotiate belonging and strangeness after a significant life event. I expect that the results from this project will develop our understanding of how people cope with significant and unexpected changes in life and the innovative ways that respond.

Invitation to Participate and Your Involvement

You are invited to participate in this research because I would like to hear your life story as you have acquired a physical disability after the age of 25. I would like to interview and audio-record your story, and ask you to nominate two close people (family members and/or friends) that will consent to be interviewed as well. The option to nominate more than 2 people is available and can be further discussed with you.

If you choose to participate, I would like to interview you up to six times and audio-record the interviews. The expected time commitment from you for this research will be 10 hours. The purpose of multiple interviews is to portray your life story and examine topics such as your life before acquiring a disability, coping with new realities, your social life, and possible changes in your identity.

I would like to interview the two people you nominated twice, so the expected time commitment from them will be 3 hours. You may choose to participate in the interviews which will be conducted with your family members and/or close friends.
Your participation is voluntary and you may decline this invitation to participate. You also have the right to withdraw from the study at any time without having to give me any reason (the same applies for your family/friends that you nominate). The organization that gave you the information about this study will not have any knowledge whether you agreed or not to participate in the study.

Prior to conducting the interviews I will arrange a meeting with you and the people you nominate to address any questions you might have about the research procedures.

**Data Storage, Retention, Destruction and Future Use**

I will collect data by audio-recording the interviews. The recordings will be stored on my password protected university drive and no other person but me will have access to this information. You and your family members and/or close friends have the right to withdraw your interview data up to one month after receiving each interview transcript. The data will be stored for six years and then will be destroyed in a secure manner.

**Autonomy and Confidentiality**

The preservation and confidentiality is paramount. The information you share with me will remain confidential and will not be shared with the other people you nominated in the research. If you choose to participate in the interviews with your nominated people, then your confidentiality will be limited to those who participate in these interviews.

Your anonymity will be protected by using a pseudonym. If the information you provide is published, this will be done in a way that does not identify you as its source. If you wish, I will provide you with a copy of each interview transcription and recording. Your comments and/or elaboration upon these interviews are welcome.

In addition, I will provide you with a list of support services in case you feel you need any additional support because of your participation in this study. If you have any further questions about my study please contact me directly or the additional contacts listed below.

**CONTACT DETAILS AND APPROVAL**

<table>
<thead>
<tr>
<th>Student Researcher</th>
<th>Supervisors</th>
<th>Head of Department</th>
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<tbody>
<tr>
<td>Shira Eisenberg</td>
<td>Assoc Prof Jay Marlowe Counselling, Human Services and Social Work <a href="mailto:jm.marlowe@auckland.ac.nz">jm.marlowe@auckland.ac.nz</a> 09 - 373 7999 Ext. 48248</td>
<td>Assoc Prof Christa Fouche Counselling, Human Services and Social Work <a href="mailto:c.fouche@auckland.ac.nz">c.fouche@auckland.ac.nz</a> 09 - 373 7999 Ext. 48648</td>
</tr>
<tr>
<td><a href="mailto:s.eisenberg@auckland.ac.nz">s.eisenberg@auckland.ac.nz</a></td>
<td>Dr Allen Bartley <a href="mailto:a.bartley@auckland.ac.nz">a.bartley@auckland.ac.nz</a> 09 - 373 7999 Ext. 48140 Ext. 48248</td>
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Approved by the University of Auckland Human Participants Ethics Committee on .... For three years. Reference number......
Appendix C: Secondary Participant Information Sheet

SECONDARY INFORMATION SHEET

Responding to Significant Life Changes: Navigating Strangeness and Belonging with an Acquired Physical Disability

Name of Researcher: Shira Eisenberg
Name of Supervisors: Dr Jay Marlowe
Dr Allen Bartley

My name is Shira, and I am a PhD student in the University of Auckland, School of Education, Department of Counselling, Human Services and Social Work. I would like to invite you to consider participating in my research project.

This Project

Rationale

I am interested in understanding concepts of “strangeness” and “belonging” after a significant life event, such as acquiring physical disability. I am also interested in the ways members of their intimate social networks (family and friends) respond to this change. I would like to interview people who have acquired a significant physical disability and learn from them how their life has changed due to the event. In addition, I would like each participant to nominate two people from their close family/friend network who I would interview twice to see how their broader social environment responded to this change.

The research goal is to have better understandings of the ways people with an acquired physical disability renegotiate belonging and strangeness after a significant life event. I expect that the results from this project will develop our understanding of how people cope with significant and unexpected changes in life and the innovative ways that respond.

Invitation to Participate

You are invited to participate in this research because I would like to hear about your experience of supporting this person with an acquired disability and how you managed any associated challenges.

Voluntary participation

Your participation is voluntary and you may decline this invitation to participate. You have the right to withdraw from the study at any time without penalty. In addition, any audio tape of your interviews will be destroyed should you decide to withdraw.

If you choose to participate, I would like to interview you twice and audio-record the interviews. The expected time commitment from you for this research will be 3 hours.

Please note that I invite the person who nominate you to participate in the research (the primary participant – that is the person who acquired a physical disability) to take part in your interview, and in such case I am not able to guarantee you full confidentiality. However, any person’s participation in your interview is subjected to your full consent.
Prior to conducting the interviews I will arrange a meeting with you, along primary and other secondary participant, to address any questions you might have about the research procedures.

**Data Storage, Retention, Destruction and Future Use**

I will collect data by audio-recording the interviews. The recordings will be stored on my password protected university drive and no other person but me will have access to this information. You have the right to withdraw your interview data up to one month after receiving each interview transcript. The data will be stored for six years and then will be destroyed in a secure manner.

**Autonomy and Confidentiality**

The preservation and confidentiality is paramount. The information you share with me will remain confidential and will not be shared with the other people in the research unless you agree to do so.

Your anonymity will be protected by using a pseudonym. If the information you provide is published, this will be done in a way that does not identify you as its source. If you wish, I will provide you with a copy of each interview transcription and recording. Your comments and/or elaboration upon these interviews are welcome.

In addition, I will provide you with a list of support services in case you feel you need any additional support because of your participation in this study. If you have any further questions about my study please contact me directly or the additional contacts listed below.

**CONTACT DETAILS AND APPROVAL**

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<td>Shira Eisenberg</td>
<td>Dr Jay Marlowe&lt;br&gt;Department of Counselling, Human Services and Social Work&lt;br&gt;<a href="mailto:jm.marlowe@auckland.ac.nz">jm.marlowe@auckland.ac.nz</a>&lt;br&gt;09 - 373 7999&lt;br&gt;Ext. 48248</td>
<td>Associate Professor Christa Fouche&lt;br&gt;Department of Counselling, Human Services and Social Work&lt;br&gt;<a href="mailto:c.fouche@auckland.ac.nz">c.fouche@auckland.ac.nz</a>&lt;br&gt;09 - 373 7999&lt;br&gt;Ext. 48648</td>
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Approved by the University of Auckland Human Participants Ethics Committee on .... For three years. Reference number......
Appendix D: Revised Ethics Approval

Research Office
Post-Award Support Services

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

10-May-2018

MEMORANDUM TO:

Assoc Prof Jay Marlowe
Counselling, HumServ & SocWrk

Re: Request for change of Ethics Approval (Our Ref. 017447): Amendments Approved

The Committee considered your request for change for your study entitled Responding to Biographical Disruption: Navigating Strangeness and Belonging with an Acquired Physical Disability and approval was granted for the following amendments on 10-May-2018.

The Committee approved the following amendments:

1. To include only primary participants.

2. Recruitment of primary participants from Israel with the same study design focus as the original ethics application.

The expiry date for this approval is 28-Jun-2019.

If the project changes significantly you are required to resubmit a new application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your study is completed.

The Chair and the members of the Committee would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at re-ethics@auckland.ac.nz in the first instance.

Please quote reference number 017447 on all communications with the UAHPEC regarding this application.

(This is a computer generated letter. No signature required.)

UAHPEC Administrators
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Counselling, HumServ & SocWrk
Dr Allen Bartley
Shira Eisenberg
Appendix E: Third Party Information Sheet

THIRD PARTIES INFORMATION SHEET
Responding to Significant Life Changes: Navigating Strangeness and Belonging with an Acquired Physical Disability

Name of Researcher: Shira Eisenberg
Name of Supervisors: Associate Professor Jay Marlowe
Dr Allen Bartley

My name is Shira, and I am a PhD student in the University of Auckland, the School of Counselling, Human Services and Social Work. I am writing to ask for your assistance with my associated research project.

The Research Project
I am interested in understanding how people cope with significant and unexpected changes in life and the innovative ways that they respond. I would like to interview people who have acquired a significant physical disability and learn from them how their life has changed due to the event. I would like to understand people’s life stories and for that I would like to interview them three times (around 5 hours in total).

The research goal is to have better understandings of the ways people with an acquired physical disability renegotiate ‘belonging’ and ‘strangeness’ after a significant life event. I expect that the results from this project will develop our understanding of how people cope with significant and unexpected changes in life and the innovative ways that respond.

Invitation to Participate and Your Involvement
I am asking for your assistance to let potential participants, who acquired a physical disability after the age of 25, know about this study. Your assistance is voluntary and you may decline this invitation. If you choose to assist, I would like your help with contacting potential participants who might agree to participate by giving them the participant information sheet. Any potential participants will contact me directly so you will not have any knowledge of who agreed to participate or not in this study to protect their confidentiality.

Data Storage, Retention and Use
I will collect data by audio-recording the interviews. The recordings will be stored on my password protected university computer, and no other person but me and my supervisors will have access to them. A copy of the interviews transcription and recordings will be made available to participants, if they wish so. Their comments and/or elaboration upon topics per their choice are welcome. The data will be stored for a minimum of six years. After the minimum storage time has elapsed, the data will be destroyed by the researcher.
Right to Withdraw from Participation
All participants have the right to withdraw from the interview at any time without giving a reason, and can withdraw their interview data up to one month after receiving each interview transcript.

Anonymity and Confidentiality
The preservation of confidentiality is paramount. No information will be reported to other people or your organization in a way that identifies the participants. Their anonymity will be protected by using a pseudonym. If the information they provide is published, this will be done in a way that does not identify them as its source. In addition, they will be provided with a list of support services in case they feel they are becoming distressed as a result of the interviews.
If you have any further questions about my study please contact me directly or the additional contacts listed below.

CONTACT DETAILS AND APPROVAL

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<td><a href="mailto:a.bartley@auckland.ac.nz">a.bartley@auckland.ac.nz</a></td>
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<td>972-58-5608660</td>
<td>09 - 373 7999 Ext. 48248</td>
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For any concerns regarding ethical issues you may contact the Chair, the University of Auckland Human Participants Ethics Committee, at the University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: humanethics@auckland.ac.nz
Approved by the University of Auckland Human Participants Ethics Committee on for three years. Reference number 017447
Appendix F: Consent Form

CONSENT FORM

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

Project title: Responding to Significant Life Changes: Navigating Strangeness and Belonging with an Acquired Physical Disability

Contact email address for researcher: s.eisenberg@auckland.ac.nz

I have read the Participant Information Sheet, and I understand the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction. I acknowledge the following:

- I agree to take part in this research.
- My participation is voluntary.
- I understand that I will be interviewed up to three times for the total amount of 5 hours.
- I understand that I am free to withdraw my participation at any time without giving a reason, and that I am able to withdraw any data traceable to me up to one month after receiving the transcript.
- I understand that data will be kept for 6 years, after which time any data will be destroyed.
- I understand that my anonymity will be protected by using a pseudonym. If the information I provide is published, this will be done in a way that does not identify me as its source.
- The organization that provided me information about this study will not have any knowledge whether I agreed or not to participate.
- I wish to receive a summary of findings, which can be emailed to me at this email address:
  __________________________

- I have been provided with a list of available support services which I can contact in case of any distress arising from this research.

Name: __________________________
Signature: __________________________
Date: __________________________

For any concerns regarding ethical issues you may contact the Chair, the University of Auckland Human Participants Ethics Committee, at the University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: humanethics@auckland.ac.nz

Approved by the University of Auckland Human Participants Ethics Committee on June 28th, 2016 for three years. Reference number 01744