REFRAMING DIAGNOSTIC LABELS AS INTERPERSONAL METAPHORS: A
SOCIAL CONSTRUCTIONIST PERSPECTIVE

by

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I declare that **REFRAMING DIAGNOSTIC LABELS AS INTERPERSONAL METAPHORS: A SOCIAL CONSTRUCTIONIST PERSPECTIVE** is my own work and all sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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Mr FN van Zyl                                    Date
Abstract

Research indicates that the number of individuals diagnosed with neurological, learning and psychiatric disorders has shown a sharp increase in recent years. An increasing acknowledgement of the importance of narratives and discourses in constructing social reality has stimulated much debate on the consequences of diagnosing individuals with such diagnostic labels. The aim of this study was to explore the ways in which such individuals construct meaning from their experiences of adapting to their diagnostic labels by reframing them as interpersonal metaphors. In service of this aim, a social constructionist epistemology was adopted and discourse analysis was used to analyse the results from three participants’ interview data. The results indicate that participants managed to construct meaning from their experiences with their diagnostic labels through a reframing process that serve to promote positive perceptions of self in relation to others. Furthermore, this meaning-construction process appears to be a reflective and interactional one, in that it relies on a negotiation of meanings between people in a retrospective fashion.

Keywords: diagnostic labels; meanings; meaning-construction; reframing; interpersonal metaphors; ecosystemic epistemology; social constructionism; language; discourse analysis; qualitative research
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Chapter 1 - Introduction

Mr. Reilly tried so hard to achieve a trance that he got in his own way and it was not until the third session that we found a useful approach. He was a member of a softball team that took play seriously. Their leading hitter in previous seasons, he had been dropped from third to eighth in the batting order because of his season-long slump. They had even taken videotapes of his struggles, which he was watching in order to figure out what he was doing wrong. I told him that it seemed to me that they were going about it in the wrong way: What he needed to do was watch himself getting hits. But they had no tapes of success (De Shazer, 1985, p. 86).

With advancements in the behavioural sciences such as psychology and psychiatry, there seems to be an increased tendency to apply diagnostic labels to various types of behavioural problems. Considering that these labels are problem-orientated and therefore highlight behavioural deficits of the individual, an interesting question is raised with regard to what the consequences of this act of labelling might be for the individual’s perceptions of self in relation to others.

The assumption that guides this thesis is that the achievement of adaptive outcomes are not so much influenced by the diagnostic label or the stigmatising discourses operating around the label, but rather by the way these discourses are framed by the individual. Therefore, unlike Mr Reilly above, the focus of this study is on the hits of ‘disordered’
individuals – I wanted to know what they are doing right and how are they framing right to turn their diagnostic labels into stories of success rather than debilitating struggles.

**Aim and rationale**

Research has shown that the number of children and adults diagnosed with neurological, learning and psychiatric disorders has shown a sharp increase over the past few decades (Wiener, 2007). An increasing acknowledgement of the importance of narratives and discourses in constructing social reality, has, however, stimulated much debate on the consequences of diagnosing individuals with diagnostic labels.

The biggest objections come from sociologists that ascribe to labelling theory and symbolic interactionism (Becker, 2008; Gove, 1980; Lofland, 1969; Rubington & Weinberg, 2008; Schur, 1971; Schur, 1983; Wright, 1984) as well as theorists that ascribe to systems theory (Anderson, Goolishian & Winderman, 1986; Efran, Lukens & Lukens, 1990; Keeney, 1979; Tomm & Sanders, 1983). The main argument against the use of diagnostic labels such as attention deficit hyperactivity disorder (ADHD) is that they tend to oversimplify and wrongfully attribute the causes of the behaviour they describe.

In accordance with the latter statement, Levine (1997) suggests that the interaction between the environment and the individual is crucial in the manifestation of problem behaviour and suggests that “the socially-constructed act of diagnosis … reduces these complex transactional processes to problems that are perceived in terms of individual
dysfunction” (p. 201). Therefore, it seems that there is concern that the labelling of problematic behaviour ignores the complex and intricate relationship between the diagnosed individual, his or her family and the wider social environment.

Another concern is for the effects of attaching a diagnostic label to individuals who exhibit problem behaviour. It seems that this concern has a double edge, in that some authors (e.g. Levine, 1997; Nylund, 2000) contend that diagnostic labels often result in individuals wrought with shame, resentment and low self-esteem, perceiveing themselves as incompetent and thinking that there is something wrong with them.

On the other hand, authors are concerned that the appropriation of a diagnostic label takes responsibility for behaviour away from the individual, resulting in a transformation of the individual from ‘transgressor’ to ‘victim’ (Du Plessis & Strydom, 1999; Rafalovich, 2005; Reid, 1996; Wiener, 2007). In fact, Reid (1996) describes the functioning of labels as follows:

> Labels provide a context within which the actions of individuals are interpreted by society. In a very real sense labels allow us to ascribe meaning to behavior and the social message of a label may lead us to ascribe different meanings to the same behavior if individuals are labeled differently (p. 251).
In conducting a literature survey it became clear that most research on diagnostic labelling focuses on either one of three broad areas: 1) the process of labelling someone as deviant or disordered (i.e. the how of the labelling process); 2) the reasons for or causes behind the labelling of deviant or disordered behaviour (i.e. the why of the labelling process); and 3) the negative outcomes of diagnostic labels for those individuals who are labelled and for society.

Inspired by the case illustration of Mr Reilly above (De Shazer, 1985) and the idea that language frames the way we perceive reality, the aim of this study was not to debate the existence or causes of neurological, learning or psychiatric disorders. Rather, in accepting that a ‘disorder’ becomes a reality for those diagnosed with it, the aim was to explore the ways in which such individuals construct meaning from their experiences of adapting to their diagnostic labels by reframing these labels as interpersonal metaphors.

My assumption is that by reframing diagnostic labels as interpersonal metaphors, individuals’ frameworks for perceiving their ‘symptomatic behaviour’ enlarge and the diagnostic label itself becomes a signal for finding new patterns of relating to others; these new patterns of relating then also hold implications for the labelled individuals’ identity constructions (or perceptions of self in relation to others).

I believe this endeavour will not only broaden our understanding of the utility of diagnostic labels, but that it will also offer some insight into the ways ‘disordered’ individuals construct the meanings of their diagnostic labels; meanings that are relevant
to their perceptions of self in relation to others, as well as to their future expectations. To state it more plainly: This exploration might offer other therapists and clients with some ‘tapes of success’.

Definitions of key concepts

With the view of commencing with this complex, often ambiguous and mostly abstract narrative exploration of meaning-construction, some of the concepts central to this study will now be explicitly defined in order to clarify their meanings as intended in the context of this study.

Diagnostic labels and events

As mentioned in the introduction to this chapter and as is explained in more detail in Chapter 2, the concept diagnostic label is often taken to signal, with high specificity, the causes and potential outcomes (prognosis) of a specific physical, neurological, learning or psychiatric disorder (Barlow & Durand, 2005). To avoid the pitfalls of objectifying this concept with absolute properties concerning cause and effect, a more fluid definition of diagnostic labels is adopted in this study. When reference is made to diagnostic labels, it is intended to refer to organising frameworks that can carry a multitude of meanings (in terms of, but not limited to cause and effect) as negotiated by the interactive exchange and coupling of meanings between an individual and his or her broader systems of living.
Closely tied to the concept of diagnostic label, the concept *diagnostic event* simply refers to a punctuated moment in time when an agreement was reached between the diagnosed individual and one or more other individuals (including a diagnostician) that a diagnostic label applies to the former as an organising framework for explaining a specific behavioural constellation.

**Reframing**

Moving from the idea that frameworks for perceiving and explaining reality are negotiated between individuals through a process of exchanging meanings, the implication emerges that reality is not absolute, but flexible and subject to change as a function of the negotiation of meanings (Andersen, 1992; Hoffman, 1992). Therefore, the act of *reframing* in this study refers to a renegotiation of the meanings of reality (specifically the meanings of diagnostic labels) and is by this definition an interactive process involving at least two individuals (the diagnosed individual and usually a friend, family member or therapist - in this case me).

**Social discourse**

Through the interactive process of negotiating and constructing the nature of reality, various meanings have come to be accepted as general truths as a result of their usefulness in illustrating and projecting cultural values. The concept *social discourses* here refers to those local, cultural truisms that are accepted as fundamental to the nature
and meaning of reality and have become implicit in the belief systems of the members of various societies and hence serve to construct the social realities prevalent in these societies (Terre Blanche, Durrheim & Kelly, 2006). An example of a social discourse is the saying: “Good fences make for good neighbours”, which illustrates the Western value of individuality.

**Interpersonal metaphors**

The value of metaphors is described by Andolfi (1989) as being ambiguous representations of reality in that they represent aspects of reality without resorting to absolute truths. Metaphors are therefore useful devices to mobilise the fluidity of meaning as they allow individuals to construct alternative meanings by capturing and making intelligible those aspects of reality that are relevant to their experiences, and organising them into meaningful frameworks for perceiving reality. Diagnostic labels as *interpersonal metaphors* are hence defined as devices to represent the interpersonal meanings that individuals construct as they pertain to their diagnostic labels and the behaviour these represent.

**Identity/perception of self**

Departing from the intrapsychic conceptualisation of identity as a stable entity that characterises individuals’ images of themselves (Meyer, Moore & Viljoen, 2003), *identity* in the context of this study takes on a more dynamic meaning. It is defined here
as an individual’s perception of self as a function of the patterns of relating and the role definitions he or she adopts in relation to significant others within a specific context of interaction. Therefore, identity is not deemed to be a stable entity to be discovered, but rather the product of interactional processes situated within interactional contexts. It then emerges that identity is taken to be a matter of defining oneself in relation to others and the context and can change as a function of the latter. Given this definition of identity, the concept is used interchangeably with the concepts *perception of self* and *definition of self* in relation to others.

**Status quo**

In systemic discourse, the concept *status quo* refers to a system’s tendency to maintain relatively stable patterns of organisation (Becvar & Becvar, 2000). In accordance with this definition, the concept of status quo as used in this study refers to an individual’s (i.e. an individual as system’s) preferred patterns of relating to and defining himself or herself in relation to others as well as his or her future expectations.

**Systemic crises**

A systemic crisis ensues when the status quo or homeostasis of a system is disrupted by input that blocks the usual patterns of systemic organisation (Becvar & Becvar, 2000). Similarly, *systemic crisis* in the context of this study refers to the blocking of preferred or
usual patterns of relating as evident in the definition of the individual’s self as a system. The systemic crisis therefore requires that new patterns of organisation be established.

**Conclusion**

In lieu of the aims of this study as outlined above, the chapters that follow each presents various aspects of my attempt to address the research problem. In Chapter 2, relevant literature on labelling theory as well as the effects of labelling, with specific focus on diagnostic labelling, is discussed. This chapter will also present a discussion of the ontological and epistemological basis of this study by giving attention to the postmodern ontology as well as the ecosystemic and social constructionist conceptualisations regarding the nature of reality, with special reference to its implications for diagnostic labelling.

Chapter 3 focuses on describing the qualitative research design as applied in this study. The specific strategies applied in selecting and interviewing participants and analysing the data are outlined and the ethical considerations as well as the trustworthiness and credibility of the research are discussed. Chapter 4 is dedicated to the presentation of the results obtained from the interviews with the three participants, using discourse analysis as analytical method.
Chapter 5 comprises of a critical discussion and integration of the results and delineates the strengths and limitations of this study before concluding with recommendations for future research in the field of diagnostic labelling.

As indicated, the attention will now shift to a discussion of the relevant literature and theories pertaining to diagnostic labelling.
Chapter 2 - Literature Review and Theoretical Foundations

In the introduction, the aim of this study was identified as an exploration of the meaning-construction processes that diagnostically labelled individuals engage in to promote positive perceptions of self in relation to others. An overview of the literature pertaining to diagnostic labels is presented here as a means to inform the pursuit of the research aim.

Literature review

The term labelling, as used in this study, is known by many names in scientific discourse, including categorising, typing or diagnosing, and refers to the sorting of people into classes that have social significance in that they offer some information or knowledge about the social, economic, medical, moral or any other form of status of its members (Lee & Craft, 2002; Rubington & Weinberg, 2008; Schur, 1971). Neurological, learning and psychiatric disorders can therefore be construed in these terms as diagnostic labels that distinguish a number of individuals with ‘shared’ characteristics or attributes and that offer some information about the medical or psychiatric status of its members (Barlow & Durand, 2005; Tomm & Sanders, 1983).

Social cognition: The imperative for labels

Social psychologists use terms such as categorisation, schemas and stereotypes to explicate the nature of the process referred to as labelling (Baron, Byrne & Branscombe,
2006; Devine, 1995). In short, they propose that a label or social category is formed through the cognitive process during which individuals build mental frameworks to organise and compact the vast amounts of information available on individuals, groups, behaviours, etc., and that represent all our knowledge and assumptions on this categorised subject. These mental frameworks are known as social schemas, whereas stereotypes refer to special types of schemas, and are defined as “cognitive frameworks that influence the processing of social information” (Baron et al., 2006, p. 571). Therefore, stereotypes are shorthand ways of evaluating, whether positive or negative, members of a categorised or labelled group by means of the traits they are assumed to share with this group. In other words, a person is stereotyped when he or she is found to be ‘guilty by association’ (of possessing traits x, y and z) through his or her membership to a labelled group.

According to social psychologists, labelling or categorisation is regarded to be a crucial part of social living, as it significantly reduces the amount and complexity of social information with which we are confronted and it facilitates simpler communication between individuals (Baron et al., 2006; Devine, 1995). For instance, one could refer to a class of individuals with mutually agreed upon characteristics when describing a particular individual to a friend. For example, a toddler is assumed by most to be a fairly short, energetic, immature, young and dependent person, and therefore one does not need to list all these traits every time you refer to a toddler.
This convenience is, however, accompanied by a potential snare in the form of reduced accuracy in social information processing (Baron et al., 2006). Besides differentiating individuals on the basis of their actual differences, labelling or social categorisation also frequently (maybe invariably) leads to the creation and maintenance of perceived (as opposed to actual) differences between individuals from different classes (Baron et al., 2006; Devine, 1995).

This view, then, supposes that labelling is 1) a linear process where the perceiver categorises a passive social actor; and 2) an inherently objective act that is based on real or intrinsic differences, but that frequently allows for subjective ‘errors’ (in the form of perceived differences) to creep in. These assumptions reflect basic limitations to understanding the process of labelling. Firstly, it does not take the reciprocal interaction between the labeller and the labelled individual into account when a specific label is negotiated (Becker, 2008; Rubington & Weinberg, 2008); and secondly, it underplays the political nature of the labelling process, which proposes that labelling always reflects ideological (and therefore temporary and subjective) distinctions of deviance (Schur, 1971). These limitations are addressed through labelling theory and the interactionist perspective.

The interactionist perspective

When referring to the labelling of deviant behaviour, Rubington and Weinberg (2008) propose that there are two ways to approach deviance. The first approach assumes that
deviance can be distinguished from non-deviant behaviour on the basis of its objective, intrinsic properties that are perceived to deviate from the widespread norms of society. Therefore a specified act, according to the objectivist approach, is defined as deviant when it breaks a valued social norm, which evokes negative reactions from society, often in the form of punishment or corrective treatment, such as in the case of hospitalisation (Becker, 2008; Schur, 1971). Given, however, that society as a whole can never be regarded as purely homogenous and therefore never fully agree on social norms, Rubington and Weinberg (2008) note that an objectivist view of deviance does not provide a sufficient account of the intricacies of labelling.

The second approach to deviance shifts the focus from the behavioural characteristics of the ‘deviant’ individual to the processes of social definition and social differentiation through which a cultural vocabulary is created that allows for individuals to be labelled ‘criminal’, ‘psychotic’, ‘depressive’, etc. (Rubington & Weinberg, 2008; Schur, 1971). Becker (2008) credits scientific research for its role in creating deviance, by pointing to the fact that

... whether talking about or studying those thought to have broken the rules, a construction of the “kinds of people” who violate rules is supported, shared, and transmitted for use in future communication about similar actors. The result is a cultural catalog of deviant social types (p. 7).
The interactionist approach rests on three assumptions (Rubington & Weinberg, 2008), the first one being that communicative interaction rests on shared symbols (including verbal and non-verbal language), which allow people to label each other and these labels consequently affect their behaviours towards each other (Schur, 1971). The second assumption is that these labels allow for the differentiation of deviant behaviour and consequently ‘deviant’ individuals (Becker, 2008). Finally, it is assumed that people’s behaviours are directed by these socially constructed deviance labels (Rubington & Weinberg, 2008).

Note that the assumptions of the interactionist perspective as described above are very similar to those of social psychologists, in that labelling is seen as fundamentally human and necessary for social functioning; that it leads to the differentiation and stigmatisation of individuals; and that labels direct people’s behaviours. However, as opposed to the social psychological explanation that describes the act of labelling as a one-way process between the typer and the typed, the interactionist perspective highlights the interactive nature of labelling, where the ‘deviant’ and society enter a process of negotiation by means of actions and reactions (Rubington & Weinberg, 2008; Schur, 1971).

In other words, the label and the dominant social discourses surrounding it informs others’ interactions with the ‘deviant’ individual, who is also affected by the label in the sense that the shared understanding of the label informs his or her interactions with others (Rubington & Weinberg, 2008). For instance, a man who is diagnosed with Major Depressive Disorder (MDD) might find that others are very supportive and careful in
engaging him, and he might accept the support, but might also become irritated with their careful attitude towards him. His reactions to others’ initial interactions with him might then be taken as evidence that he is indeed helpless and irritable and therefore reinforce the MDD label.¹

These label-informed interactions feed off each other and can produce a variety of relational outcomes, including the self-fulfilling prophecy (as described in the preceding example), typecasting and recasting (Rubington & Weinberg, 2008). Typecasting occurs when a deviance label is so well known and accepted by society that reactions to such a labelled individual become automatic. For example, a community might immediately round up all known paedophiles living inside its borders as soon as a child goes missing, without any proof to substantiate that they are involved in the disappearance. Finally, recasting refers to societal reactions that are geared towards evoking label-incongruent behaviour in the ‘deviant’ individual. For instance, the MDD patient referred to above might feel encouraged to take on more responsibilities to counter helpless feelings and behaviour and thereby act in a way that is incongruent with the stereotype associated with MDD.

The interactionist perspective therefore emphasises the tendency of labels to induce the behaviour it describes, via people’s reactions to the deviant label. Frank Tannenbaum describes it simply:

¹ It is important to note that this sequence of interactions can by no means be taken to be a linear cause and effect chain, as this would constitute a punctuation of the sequence of events where one action is assumed to cause another without recognising that they are in a circular causal loop. Thus it becomes futile to say that A caused B, as another punctuation would show that B caused A (Efran, Lukens & Lukens, 1990). This will be discussed in more detail in a later section.
The process of making the criminal ... is a process of tagging, defining, identifying, segregating, describing, emphasizing, and evoking the very traits that are complained of ... The person becomes the thing he is described as being (Tannenbaum, as cited in Rubington & Weinberg, 2008, p. 3).

From this discussion it is apparent that the interactionist perspective contributes considerably to the understanding of labelling of deviance and its effects for the labelled individual and society. For instance, this perspective justly credits the important role of language and social discourse in constructing deviant behaviour through the labels we attach to ‘deviating’ individuals (Becker, 2008). Related to this, it acknowledges the cultural context in which deviant behaviour occurs, as various cultures differ in the types of valued and shunned behaviours and the vocabulary that correspond to these categories (Rubington & Weinberg, 2008).

Although it recognises the interactive nature of the labelling process, the interactionist perspective is, however, still preoccupied with what leads to the labelling of a person and what the effects of labelling are. This inevitably leads to a punctuation of the interaction as a linear sequence where one party (e.g. society’s rules) causes the other (e.g. the breaker of society’s rules) to be viewed or acted to in a certain way. Keeney (1979) describes the dangers of such linear thinking:
... when we use a linear epistemology “we abstract from relationship and from the experiences of interaction to create ‘objects’ and to endow them with characteristics” ... Ecosystemic epistemology requires that we undo these substantive abstractions and begin seeing patterns of relationships (p. 120).

Therefore, in simple terms, such abstractions ignore the wholeness of the situation and reduce intricate patterns of relationships to overly simplistic linear ones. Although the interactionist perspective describes labelling as an interactive, societal process, this interactive description still punctuates a sequence of events between society and the labelled individual in a linear chain. This punctuated sequence is presented in the following contingencies: ‘deviant’ individuals behave in ways that necessitate society to create labels and therefore society creates labels that reinforce the ‘deviant’ behaviour of ‘deviant’ individuals. Such linear reductions then lead to a situation of ‘which was first, the chicken or the egg?’. Kugelmass (1987), working in an educational setting, made a fitting statement in this regard:

[T]he identification of someone as disturbed is a complex phenomenon that involves more than the child and the labeller. It is a subjective matter that involves the systems in which both operate, and the interactions between them (p.25).
In trying to understand labelling and its effect, it seems necessary to move beyond the labeller, the labelled and their interaction to consider the entire ecology in which labelling occurs.

**Towards an ecological perspective**

Efran et al. (1990) suggest that the pursuit of cause-effect chains

... *can be an unproductive mental game. Often we don’t need to traffic in causal attributions at all. We know what we like even when we don’t know why we like it. We know that when our brother was late, we got upset. We also know that when he apologized in a particular way, our distress vanished. That much we can be certain of, and it is important. The rest is often idle inference* (p. 101).

Efran et al. (1990) are also of the opinion that causes and effects are created by people through the subdivision of phenomena (including experience) into parts (Lifschitz & Fourie, 1990). Therefore, social experience and social living do not intrinsically exist with special laws determining that event A would lead to outcome B (Fourie, 1994). Rather, social systems constitute whole systems (Lifschitz & Fourie, 1990) where cause and effect is purposeless, in that its invention inevitably leads to tautologies. In other words “[a] description is turned into a purpose that is then asked to account for the description” (Efran et al., 1990, p. 99). A fitting example of such a tautology was
described above – the individual with MDD. This different model for conceptualising the world in terms of wholeness emerged within the ontological shift known as postmodernity and is known as ecosystemic epistemology.

The postmodern explanation

According to Sey (2006) “postmodernism is a broad term for many different approaches that set themselves up in opposition to the coherence and rationality of the modern world” (p. 524). From this description, one is able to infer that postmodernism incorporates a different way (from modernism) of understanding the world and the way in which people relate to it. Modernist approaches (such as positivism) emphasise the ‘knowability’ of ultimate truths, which assume that researchers can transcend their own subjectivity and observe the world in an objective, value-free manner (Fourie, 1994; Sey, 2006). Therefore, where modernity postulates the ‘discovery’ of natural and linear cause-effect laws, postmodernism rejects the idea of a single truth, and rather acknowledges the possibilities of multiple and relative realities that are constructed by the meanings that people attach to events (Sey, 2006).

Ecosystemic epistemology and social constructionism

In keeping with the postmodern revolt against the reduction of reality to linear cause-effect laws, second-order cybernetics posits that a system (such as a society with its categorised subsystems) is defined as being whole, self-referential and autopoietic,
among other elements (Becvar & Becvar, 2000). The wholeness of a system implies that any description of what is happening in the system is self-referential (Fourie, 1994). This simply means that, in systems, simultaneity of interactions occurs where the describer has to include himself or herself in that which he or she is explaining. Therefore, any “functions are functions of themselves … interactions … intersect with themselves [and] properties … compute themselves …” (cited in Becvar & Becvar, 2000, p. 79). Since there is ‘simultaneity of interactions’, the act of labelling behaviour as disordered is both the cause and the effect of the individual’s disordered behaviour that is being typed by the label, and the same is true for the ‘disordered’ individual’s behaviour towards others and others’ behaviour towards him or her.

Given this explanation of systems, and if one accepts that society as a system functions as a whole system (Fourie, 1994; Lifschitz & Fourie, 1990), it becomes clear that simplified and reductionistic explanations of diagnostic labels and its causes and effects are irrelevant and even distracting. As Efran et al. (1990) comment:

> [E]xplanations attempt to condense and encapsulate still larger living patterns. In the mental health field, such condensations erroneously amplify the determinative importance of particular incidents over everyday drift. They yield a false picture. In life as it is lived, all successive moments “count” – not just the special few that are embroidered into our narrative tapestry (p. 92).
In keeping with this argument, Kugelmass (1987) argues that diagnosing a person and thereby labelling him or her as deviant should move away from seeking the cause of symptomatic ‘diseases’ within individuals and rather place the behaviour in its proper ecological context.

For instance, referring to ADHD, Du Plessis and Strydom (1999), Rafalovich (2005) and Reid (1996) highlight the observation that ‘ADHD children’ only exhibit impairment in attention and behaviour in some situations (usually school), whereas at other times (such as when they are immersed in a stimulating activity) they are virtually undistinguishable from their ‘normal’ peers. This observation highlights the importance of the social environment in which the problem behaviour occurs. The symptom (deviant behaviour) therefore becomes a sign of “discordance” in the system in which it is imbedded (Kugelmass, 1987, p. 19).

**Symptoms as functions of stability**

This idea of symptoms as communicative signals of the nature and workings of the interpersonal relationship systems such as the family, community or even nation is one that has received a lot of attention from systems thinkers and family therapists (e.g. Haley, 1963; Keeney, 1979; Tomm & Sanders, 1983; Watzlawick, Bavelas & Jackson, 1967). Keeney (1979) describes symptomatic behaviour as relationship metaphors, thus highlighting its communicative function as a compounded illustration of what is
happening in the relationship. In addition to this, Haley (1963) suggests that symptoms or deviant behaviour, in fact all behaviour, should be seen to be strategic in nature.

In other words, symptomatic behaviours are tactics in human relationships, in that these behaviours serve a particular function for the person performing it, as well as in the relationship system that forms the context for its manifestation (Haley, 1963; Watzlawick et al., 1967). In simple terms, symptoms can be described as “a way of dealing with, perhaps disarming, another person” (Haley, 1963, p. 5).

The idea of symptoms as strategies and relationship metaphors has the important implication that the symptoms (or deviant behaviour) have a stabilising effect in the relationship system. This is evident in Keeney’s observation that the treatment and subsequent relief of symptomatic behaviour, without restructuring the relationship, often leads to “a transfer of symptomatic expression to another site [in the system]” (Keeney, 1979, p. 120). Tomm and Sanders (1983) argue that labelling such deviant behaviour, i.e. diagnosing the ‘identified patient’ (IP), actually risks stabilising the system, such that the IP becomes the scapegoat and regular (or invariable) site of symptomatic expression. This problem is compounded by the tendency of diagnostic labels to limit subsequent behaviours, as the directive nature of diagnostic labels serves to inform family and therapist observations and behaviours toward the IP (Tomm & Sanders, 1983).

Efran et al. (1990) make a similar statement about the restrictions of diagnostic labels, for “in their quest to be precise – to pin problems down in objective, concrete terms – people
are labeled, problems are named, and flexibility is lost” (p. 89). Therefore, a pattern of relating is formed or reinforced by the way the problem behaviour is framed through the application of a diagnostic label, and alternative ways of framing the problem and thus behaving become pseudo-impossibility. It would seem then that the power of diagnostic labels to ‘disable’ emanates from the communicative value they serve in order to make sense of the shared reality of the role-players in the ‘problem’ system.

**Social foundations: The importance of language in constructing reality**

The value of recognising the communicative value of diagnostic labels can best be made salient by considering the recent shift towards acknowledging the constructive power of language. By shifting their focus to language, social constructionists recognised the important role of language in shaping social reality (Fourie, 1994). More specifically, social constructionism postulates that reality is constructed through a social process characterised by mutual agreement between people on the nature of reality, whereby shared meanings, beliefs and values are attained (Young & Collin, 2004).

In achieving this agreement, Sey (2006) suggests that linguistic structure plays an important mediating role in constructing reality. It is through language and the way it is put to use that realities are shaped and transmitted from one generation to the next through a system of shared meanings, known as culture. The social constructionist epistemology links very closely to the postmodern worldview, in that the idea that
different realities are created by means of a social process of shared meanings inherently allows for the possibility of multiple and relative realities.

This shift in thinking came about with the consideration of the ideas of Bateson in family therapy, who suggests that power is a social construction (Cecchin, 1992). This power, which families are said to battle for, was no longer seen as an entity to possess, but rather became a creation of people relating to one another in a specific context and who act as if it exists. For example, the power an authoritarian husband holds over his wife cannot be divorced from her submissiveness and the mutual agreement between them regarding the nature of their relationship. Each play a role in constructing that power through what Maturana (1974) calls structural coupling. This means that families are organised the way they are because each member couples his or her behaviour to fit with the family environment.

Therefore, everything that happens within a family happens only because it could happen, and any attempt to explain what happened is an act of fiction. Thus, people’s explanations of events are not the events themselves, but represent specific ways of organising those events, which depend on the vantage point from which those events are observed.

Therefore, social constructionists reject the idea of an underlying structure or order in any phenomenon being studied (Andersen, 1992; Cecchin, 1992; Fourie, 1994; Hoffman, 1992). For instance, this view would suggest that any structured patterns observed in a
family are not inherent qualities of that family, but rather constructed through social negotiation via the medium of language. Thus, the order we observe, is the product of a social process whereby meanings are created (Fourie, 1994) and that can and do change over time. In other words, because our observations are informed by the language we use to describe them, these observations will always reflect political and ideological power relations among those who describe and those who are described (Hoffman, 1992), and may change relative to changes in society.

In a similar vein, Efran and Clarfield (1992) argue that from a social constructionist viewpoint, it is true that no-one can know an objective reality, but that everyone has (and is entitled to have) a preferred way to conceptualise reality. Such a reality should, however, not be mistaken for the truth, but acknowledged as one of multiple (value-laden) truths.

Linking to the systemic idea of observers as self-referential systems, Frugerri (1992) posits that any knowledge about an individual’s system is seen as an ongoing, self-referential construction that relies on the observer’s description of the system through subjective language and thus relating what he or she sees in terms of his or her previous experiences. The observer therefore creates and becomes part of the system he or she describes, purely through his or her act of observing and describing through language (Fourie, 1994). This act of observing and describing then also changes the observer’s relationship to the system in a continuous fashion as this is an interactional, circular
process in which each act of observation adds something new to the system (Fourie, 1994; Frugerri, 1992).

In explaining this idea of self-reference, Andersen (1992) holds that

... we do not relate to life ‘itself’ but to our understanding of it ... [and furthermore] we strongly participate in creating our understanding of life ... [and consequently] there are as many versions of a situation as there are persons to understand it (p. 61).

Thus the observer can no longer be seen as separate from and objective with regard to that which he or she describes. This is referred to as the organisational closure of self as a system (Becvar & Becvar, 2000), meaning that one cannot observe the world without referring to your own subjective experiences of the world.

Given that each person relates to his or her own version of reality, Efran and Clarfield (1992) note that it is tempting to argue that social constructionism amounts to solipsism (i.e. that because there is no objective truth, there is no standard against which to evaluate the validity of any assumptions about reality). It should, however, be kept in mind that any person’s assumptions about reality is situated within a social domain (Cecchin, 1992), meaning that the assumptions we make of reality are mediated by the assumptions of others as well as the broader social narratives that set the boundaries of our assumptions of reality (Efran & Clarfield, 1992).
Cecchin (1992) makes a similar observation and argues that people not only construct meanings to make sense of reality through social interaction, but also that the significance of such interaction becomes a way of defining the self in a relationship with the world. People’s interactions (mediated through language) are thus seen to be efforts to construct realities, which hold with it the limits and opportunities we are faced with as individuals related to that reality.

**Language: Both friend and foe**

Since the way we define or frame our interactions with others has a big impact on what we recognise the possibilities for our behaviour to be, it follows that language becomes the crucial element in creating and resolving problematic systems (Efran et al., 1990). Anderson et al. (1986) describe the way an ecology of ideas are formed around

... the shared, cognitive, and linguistic discourse through which we derive meaning, and out of which we create the realities of coordinated action systems. Through language individuals interact with and coordinate behaviour with others in a variety of ways. This can even be ways that are thought of as problems (p. 6).

Therefore, a person’s behaviour only becomes deviant or problematic when it is languaged or framed as deviant or problematic (Fourie, 1994; Terre Blanche, 1998). For instance, any person’s fear response to spiders, heights, water or his or her own shadow is
merely a bodily reaction to objects or situations. The body merely responds to a stimulus without evaluating the appropriateness or intensity of the response. Efran et al. (1990) argue that “fears only seem disproportionate to danger when they belong to another person or are evaluated from another perspective” (p. 91).

Therefore, the person only becomes a phobic when his or her behaviour is evaluated from an outside perspective and framed in a problematic fashion, i.e. labelled as disordered. In this way agreement is reached that the person has a problem and a ‘coordinated action system’ forms around the identified problem – what Anderson et al. (1986) call a problem-determined system, where the organisation of the system and the IP’s role in it are altered by the admission that there is now a problem.

An example of such a problem-determined system would be the organised system that forms when a family comes to the conclusion that their child’s bedwetting is a problem that needs to be dealt with. The child’s bedwetting could become a problem when there is disagreement between the parents on how to manage this behaviour. This might raise issues in the marital relationship regarding who is in charge and who takes control over which scenarios and might also lead to parental conflict. The bedwetting behaviour might escalate as the mother and father present with a disjointed reaction to the bedwetting as each attempts to assert their parental and marital authority. In turn the child might become confused with regard to what is expected of him. The mother might insist that the behaviour is normal and might resent her husband’s suggestion to seek professional help, whereas the husband might blame his wife for not caring enough to do something to help
the child. Thus the initial agreement that the bedwetting needs to be managed determined a distinct pattern of organisation in the family system around the child’s bedwetting – the problem determined the workings of the system (Anderson et al., 1986).

Critical approaches (including structuralist, post-structuralist and Foucaultian theory) also highlight the unequivocal role of language in creating the realities that we so easily take for granted (Fourie, 1994; Terre Blanche, 1998). For instance Althusser (as cited in Terre Blanche, 1998, p. 140) describes the means by which Western democracies are produced and maintained by “Repressive State Apparatuses”, such as prisons, institutions, etc., in conjunction with “Ideological State Apparatuses”, such as the medical profession, which depend on words to exert domination and submission among the powerful and the powerless classes:

...The realities of the class struggle are ‘represented’ by ‘ideas’ which are ‘represented’ by words. In scientific and philosophical reasoning, the words (concepts, categories) are instruments of knowledge. But in political, ideological and philosophical struggle, the words are also weapons, explosives or tranquilizers and poisons. Occasionally the whole class struggle may be summed up in the struggle for one word against another word. Certain words struggle among themselves as enemies. Other words are the site of an ambiguity: the stake in a decisive but undecided battle (Terre Blanche, 1998, p. 140).
While these approaches emphasise the importance of the actual words, phrases and other units of language that construct the reality of some class (such as psychiatric patients) at the will of another class (such as doctors and psychologists), Searle and others (as cited in Terre Blanche, 1998) see the power of language to reside in “speech acts” (p. 144) rather than in words. Terre Blanche (1998) describes the process of a conversation to illustrate the importance of the interaction between ‘speaker’ and ‘hearer’, which affords words their power. As such the speaker needs to mean something and the hearer needs to understand what is meant for communication to take place.

Apter (as cited in Kugelmass, 1987) illustrates the role of such interactions in creating deviant behaviour as

... a disparity between an individual’s abilities and the demands and expectations of the environment – a “failure to match” between the child and the system. It is not the child alone or the environment alone that causes emotional disturbance. Rather it is the interaction between them that creates a discordance and disrupts the system (p. 19).

This description highlights the importance of the framing of the child’s behaviour through environmental expectations. The child needs to behave in a certain manner, and the social ecology needs to evaluate this behaviour against certain expectations in order to define a problem, usually in the child. Language is the medium through which such expectations are known and shared.
From an ecological perspective then, language becomes the medium for creating and resolving problems (Fourie, 1994). When it is said that language creates the disorder a person is said to exhibit, it is not meant that such behaviour does not actually exist. Rather it is suggested that such behaviour is merely behaviour, which, in the interpersonal context or ecology it occurs, is framed as problematic by the language and shared meanings attached to it (Efran et al., 1990).

Although the social constructionist view posits that clients’ problems are situated in a system of language, it is false to assume that in psychotherapy we as psychologists only deal with interpretations of, or metaphors for, their ‘real problems’ (Efran & Clarfield, 1992). This is because the idea of different hierarchical levels in human functioning such as overt and covert messages and superficial symptoms versus the deeper underlying causes is rejected by social constructionists. Instead Efran and Clarfield (1992) argue that each of these ‘levels’ could act as a context for another and therefore has equal horizontal standing as opposed to hierarchical vertical standings.

Diagnostic labels then are not merely the surface concept that refers to an underlying problem, but rather become the context for the ‘problem’, in that the discourses accommodating them frame the experiences of the individual in a specific (usually dysfunctional) manner. In another interpersonal context, however, the same ‘problematic’ behaviour might be framed as highly desirable, adaptable and endearing, depending on the shared meanings and language used to evaluate the behaviour.
Cecchin (1992) argues a similar point in claiming that we not only negotiate the limits of our personal agency through social interaction, but that it is also through such interactions that we can extend our definitions of self and the problems we face in order to offer possibilities for more personal agency. Linking to this idea, Andersen (1992) postulates that psychotherapeutic conversation can be defined as an individual’s search for new descriptions and definitions of the self that he or she would be most comfortable with.

**Ecological and narrative conceptualisations of psychotherapy**

The goal of psychotherapy, from a social constructionist viewpoint, is to utilise the discrepancies in meaning that exist between the therapist’s and client’s descriptions of reality to overcome the limitations of old narratives and co-construct new and different stories with more possibilities for clients (Cecchin, 1992; Fourie, 1994).

For instance, consider the predicament a woman would find herself in when a certain interpretation of her religious convictions excludes or contradicts the possibility of being true to her sexuality. Such contradictions constitute the problems that individuals are faced with, and psychotherapy, from a social constructionist viewpoint, aims at enlarging the boundaries of the playing field to make space for the individual’s apparently contradictory preferences.

By conversing in a manner that illuminates the different ways that the therapist and client define the problem, a context is created where both can negotiate a new frame that
represents the shared meanings that co-evolved between therapist and client (Andersen, 1992; Cecchin, 1992; Frugerri, 1992). The woman’s contradiction described above then clears up when her definition of herself or her situation is expanded to integrate her previously conflicting preferences in a harmonious way. Therefore, our problems arise in a social domain through language, but it is also through language that we can reframe our problematic definitions of self in order to construct solutions.

Psychotherapy then becomes an endeavour to restructure the problematic system (Keeney, 1979) by reframing a person’s behaviour (via societal discourses) in a way that allows for better outcomes to become readily apparent (Efran et al., 1983) and that alters the relatedness between the IP and others in the system. If the goal of psychotherapy is to utilise discourses to reframe personal narratives and extend the limitations placed on our agency, it could be argued that people who have adapted to their diagnostic labels somehow reframed the meanings that they attached to their ‘problem behaviours’ to allow for more personal agency and extended the limitations placed on their personal freedom by the previous meanings they attached to these behaviours.

In other words, just as diagnostic labels have the potential effect of making a person define himself or herself as a ‘deviant’, ‘victim’ or ‘outcast’, they could also, depending on the discourses employed by the individual and the way they are related to each other, serve to define the individual as a ‘hero’, ‘conqueror’ or ‘victor’.
For instance, a man with the diagnosis of anxiety disorder is faced with a multitude of discourses surrounding his diagnosis. Firstly, gender discourses accompany the fact that he is a man and advocates that men should exude rationality, courage, masculinity, fearlessness and the like. Secondly, medical discourses, which accompany anxiety disorders, suggest that phobias are exaggerated, irrational and unfounded fears. When utilising these discourses in framing his experience of being diagnosed as a ‘phobic’, he can easily define himself as a ‘wimp’, since he is excessively fearful, overreacts when faced with the object he fears and, in addition, his actions seem to be irrational and illogical.

Therefore, the discourses, when organised in this way, present the man with an emotional contradiction, in that his fears cannot be reconciled with his masculinity, which would likely heighten his experience of distress. However, by reorganising these discourses, the meanings he attaches to his ‘disordered’ behaviour can be framed in a more useful way, as when he might recognise that he is faced with most men’s biggest fear, namely being emasculated by a ‘mental disorder’, and might rise to face that fear head-on. This reframed explanation of his experience serves to expand the limitations placed on his masculinity by the former framing and consequently resolves the emotional contradiction that existed before. He can now define himself as a very brave man that stood up to and conquered the fear of being emasculated by an anxiety disorder.
Defining the self: A never-ending, ever-evolving story

Given the role of language (in this case, specifically the language surrounding diagnostic labels) in constructing interpersonal realities, it follows that language also holds important implications for the definition of self of an individual. When referring to the notion of self, social constructionists reject the modernist tendency of defining the self as a structure-determined inner reality, consisting of emotions, cognitions, etc., and that assumes a fairly rigid form over the lifespan.

Rather, according to Hoffman (1992), the self is viewed as a continually evolving entity that waxes and wanes over time, much like a “stretch of moving history” (p. 10). She maintains that any person’s experience of himself or herself is imbedded in a relational field where changes in others’ reactions to him or her affect the way he or she experiences the ‘self’, and vice versa. Therefore, the ‘self’ is described in terms of circular interactions that cause it to evolve and change shape over time.

Andersen (1992) also highlights the interactional nature of the concept of self and maintains that by using language, people express and construct their being by defining themselves in discussions with themselves and others. Thus, any interactions or events are related to one’s construction of the self through the language that is used to describe oneself in relation to such events. Andersen (1992) goes so far as to say that “talking with oneself and/or others is a way of defining oneself. In this sense the language we use makes us who we are in the moment we use it” (p. 64).
Related to the concept of self as a continuously evolving process, the idea of normal human development also takes a different meaning when viewed from a constructionist viewpoint. Hoffman (1992) posits that the traditional psychological given that normal human development occurs in developmental stages is unwarranted in that there is great variability regarding human development and to single out one ‘optimal’ route is to step into the same trap of a singular truth. Thus, given the scientific discourses on diagnostic labels, it is easy to come to the conclusion that such labels refer to ‘real’ underlying conditions that manifest in behavioural and interactional disturbances and that are the consequences of a deviation from the optimal route of development.

Such a conclusion, however, ignores the crucial fact that the ‘disorders’ that are spoken about are products of the linguistic activities that occur between agents of the institutional and cultural contexts that carry the values and expectations of society at large (Hoffman, 1992). Therefore, it is through cultural and institutional politics that neurological, learning and psychiatric disorders are defined and framed in specific (read disabling) ways. Hoffman (1992) citing Gergen, highlights the trap of generalising the developmental flow of human functioning:

\[It is becoming increasingly apparent to investigators in [the domain of social constructionism] that developmental trajectories over the lifespan are highly variable; neither with respect to psychological functioning nor overt conduct does there appear to be transhistorical generality in\]
lifespan trajectory ... A virtual infinity of developmental forms seem possible ... (p. 11).

Given this view of the self, and the multitude of developmental pathways open to people, it seems to open new avenues for thinking about the effects that diagnostic labels have on those people diagnosed with them. Scientific discourse seems to be filled with debate on the reasons for using or not using diagnostic labels, as if the labels themselves have intrinsic qualities that make them good or bad.

Also, in debating on the value of diagnostic labels it is assumed that the effects of diagnostic labels are invariably experienced the same across society, ignoring the idea that people construct their realities in a continuous process of framing and reframing their experiences by playing with the discourses available to them (Andersen, 1992; Anderson & Goolishian, 1992). This is because any discourse, by way of its interactional and thereby political nature, promotes the validity of some idea over another and the legitimacy of some topic over another (Hoffman, 1992).

It can therefore be said that people are immersed in writing the stories of their lives. They borrow words, sentences, phrases and concepts from a cultural stockpile; they string them together, cut them apart, format their meanings and paste them in varying orders. While what is told at a specific moment in time might be a story of romance, an epic tale of struggle or an horrific battle for life, it should be remembered that the genre cannot be named or fixed until the last page is turned.
Positive outcomes of labelling?

It would seem from the foregoing discussion on labelling and its effects that authors agree on the fact that diagnostic labels have dire consequences for the individuals being labelled. These consequences can be grouped into three categories, namely that:

1) diagnostic labels can lead to individuals being stigmatised according to the generic characteristics to which the label refers;

2) diagnostic labels inform people’s expectations of labelled individuals, thereby affecting the ways they relate to these individuals and vice versa. This can lead to self-fulfilling prophecies where the diagnostic label evokes the behaviour it represents; and

3) diagnostic labels tend to frame our thoughts on a specific phenomenon, thereby restricting the recognition of alternative ways to frame this phenomenon.

In other words, diagnostic labels tend to frame symptomatic behaviours in debilitative, intrapersonal terms – a disorder that afflicts the person. It is apparent that these consequences are not independent effects of diagnostic labelling but overlapping and intertwined processes that are punctuated in a certain way.

If one accepts the idea that language is the crucial element in the creation of disordered and deviant behaviour, it should follow that the consequences of diagnostic labelling as described above can be framed as potentially positive outcomes of labelling. In fact, Reid
(1996) suggests that diagnostic labels (referring specifically to ADHD) serve a therapeutic function, as they allow the afflicted parties to attribute a cause to the problem behaviour and consequently get a grasp on the situation, which enhances feelings of competency. Furthermore, diagnostic labels provide a means for appropriating services (such as additional educational assistance) and protection (such as social and/or disability grants) that might not have been available otherwise.

Herman and Miall (1990) describe a similar set of positive outcomes (as experienced by respondents in their study) of stigma related to diagnostic labels. They found that diagnostic labels can lead to

1) the legitimation of deviant behaviour, thereby excusing these individuals from personal responsibility for their actions, as these are now attributed to the disorder. People therefore tend to place less blame on psychiatric patients for their past and present deviant acts, which could ease feelings of personal guilt;
2) exemption from usual social roles and obligations, meaning that society’s expectations of these individuals are somewhat altered or reduced, thereby potentially reducing stress related to social expectations;
3) access to adaptive opportunities, meaning that labelled individuals learn to utilise their diagnostic labels in order to get access to shelter, health care, food, etc.;
4) the strengthening of family relationships, in that the family unites to support the ‘disordered’ family member; and
5) experiences of personal growth, where the labelled individual gets to learn something of himself or herself and his or her behaviour through self-reflective techniques and analysing people’s reactions toward him or her (Herman & Miall, 1990).

Instead of viewing these outcomes as separate positive outcomes to the negative ones outlined above, these can be seen to be alternative ways of framing the experiences of individuals who have been diagnosed as mentally disordered. Herman and Miall (1990) duly state that “the possession of a discredited attribute can be a positive experience dependent on actor definitions and actions” (p. 264).

For instance, 1) can be seen as a positive framing of the view that diagnostic labels are debilitative; 2), 3) and 4) as positive frames for the view that diagnostic labels lead to negative reactions and secondary gain, which reinforce the disordered behaviour, for the symptomatic behaviour can be defined as an asset that provides adaptive opportunities, reduces personal stress and mends family ties; and 5) as a positive frame for the view that diagnostic labels tend to crystallise the problematic organisation of the system by identifying a scapegoat or IP, because the personal growth can lead to changes in the way the labelled individual relates to others.

Herman and Miall (1990) mention a potential societal gain of labelling: “[L]abelling an individual deviant may in fact conventionalise deviant behavior and return the individual to a more acceptable way of acting …” (p. 264). A contemporary example of this
outcome is the current ‘normalisation’ of same-sex relationships around the world, where numerous countries are contemplating the legalisation of gay marriages. Thus, same-sex sexuality is in the process of being accepted as a legitimate and conventional life path rather than as deviance or abnormality.

Depending on the labelled individual’s acceptance of them, all these positive frames can alter the individual’s position in the problem-determined system, such that the system’s organisation is altered, with the symptoms possibly becoming obsolete. Therefore, instead of weighing the positive and negative consequences of diagnostic labelling against each other, the focus can be shifted towards the manner in which labelled individuals construct and frame their experiences and potential outcomes utilising the social discourses surrounding a particular diagnostic label.

The idea is that discourses are discourses and behaviours are behaviours; the difference that makes a difference, however, is the way these are put together and related to each other to construct a reality of experience where the identified problem is no longer a barrier to adaptation, but a lesson learned in construing alternatives. This holds the important implication that due consideration be given to the dominant discourses that accompany any given diagnostic label, and the way in which they inform people’s understanding of neurological, learning or psychiatric ‘problems’ when constructing their worlds with its limits, so that these assumptions can be challenged. Such an examination of assumptions would constitute the critical role that Young and Collin (2004) ascribe to social constructionism.
In explaining the critical stance that social constructionism takes, Young and Collin (2004) contend that “most social constructionisms overtly challenge orthodox, positivist assumptions” (p. 377) and also cite Gergen saying that “social constructionism asks a new set of questions – often evaluative, political, and pragmatic – regarding the choices one makes” (p. 377).

When adopting such a critical stance it is important to consider the important distinction that Andersen and Goolishian (1992) draw between local meanings and dialogue and broadly held cultural sensibilities, the former referring to “the language, the meaning, and the understanding developed between persons in dialogue…” (p. 33). Andersen and Goolishian (1992) recognise the importance of local meanings to be situated in the fact that “there is a range of experiences and a way of knowing these experiences that is sufficiently different from ‘knower’ to ‘knower’…” (p. 33). It therefore becomes apparent that the effects of diagnostic labels cannot be abstracted from the context in which they are understood by the person who is labelled.

Taking these points into consideration, it becomes futile, in my opinion, to debate the goodness or badness of any diagnostic label. Rather, I choose to acknowledge that each participant’s reality is constructed by the bestowal and/or acceptance of the diagnostic label, the way his or her social world organises itself in relation to that label (i.e. how do
others react to the label and how does it affect his or her relationships?), and consequently the meanings he or she attaches to this label.

The way all these experiences are put together and framed would constitute whether the diagnostic label is experienced as good or bad, and whether it would lead to alternative and adaptive outcomes for the labelled individual. Considering the foregoing discussion on psychotherapy as a collaborative attempt to reframe a problem in order to allow for flexibility and alternatives, it would seem hypocritical of psychotherapists to frame diagnostic labels as inherently restrictive, stigmatising and unproductive, as this framing itself is restrictive and inflexible.

As Efran et al. (1990) propose, one can get caught up in ideological debate on complex issues of trivial importance when one takes too serious the idea that certain distinctions are so fundamental that they can yield permanent objective truths. Therefore, scientific endeavour in this view ceases to be a quest for the question that would yield the answer. Rather, the goal becomes to ask questions in such a way as to open new doors for alternative answers to become a possibility, steering clear of those absolutes that are no better than wool over the eyes.

**Conclusion**

As mentioned before, the aim of this study is to explore the ways in which individuals construct meaning from their experiences of adapting to their diagnostic labels by
reframing these labels as interpersonal metaphors. Accordingly, the focus falls on the meanings participants ascribe to their diagnostic labels and the implications that these meanings have for their perceived outcomes in various aspects of life. As discussed in this chapter, my assumption is that individuals collaborate in the construction of certain realities and that one cannot assume that one truth holds true for all.

From a social constructionist point of view, my hope for this study was to raise the questions that challenge the dominant, ideological scientific discourses that still reign today. In other words, does a diagnostic label help the individual or hinder him or her; and are the outcomes of diagnosed individuals an implicit function of the stigmatising discourses that accompany their diagnostic labels, or are they functions of the way in which these discourses are organised into a frame for viewing reality?

With these points in mind, the focus in Chapter 3 shifts to a description of the qualitative research design and its methods of data gathering and data analysis as the means to address the aims of this study.
Chapter 3 – Research Strategy and Guiding Methods

Having discussed the aim of the study and reviewed the literature pertaining to diagnostic labelling, the focus in this chapter shifts to an exposition of the guiding research methods and processes to achieve the research aim. A qualitative approach to the investigation has been posed and is described in terms of its applicability to direct the research endeavour. In addition, the venture into the realm of application is presented with reference to the identification of suitable participants, the means of collecting data, as well as the analysis strategy employed. Finally, the chapter concludes with an exposition of relevant ethical considerations as well as a clarification of the credibility and trustworthiness of the study.

The qualitative research design

Considering the aim of the study, namely an exploration of the meaning-construction processes that individuals diagnosed with neurological, learning or psychiatric disorders engage in by reframing their diagnostic labels as interpersonal metaphors, it was deemed to fit well with a qualitative research approach. In support of this fit, Durrheim (2006) is of the opinion that “[q]ualitative methods allow the researcher to study selected issues in depth, openness, and detail as they identify and attempt to understand the categories of information that emerge from the data” (p. 47). Thus, qualitative research is not concerned with the identification of cause-effect relationships, but rather enquires about individuals’ lived experiences, thereby attempting to obtain a meaningful understanding of those individuals’ experiences.
There are, however, differences in the ways that qualitative research is approached by different researchers. Murphy and Dingwall (2003) outline the diverging viewpoints among qualitative researchers regarding the nature, goals and purpose of qualitative research endeavours, arguing that there seems to be widespread disagreement regarding the role of qualitative research within the scientific community.

Some qualitative researchers contend that there is an objective reality that can be known through systematic and rigorous observation and enquiry, and that two different observers, when placed in the same context and view a situation from the same angle would produce the same account of that event, given that their observations were scientific. This is known as the realist approach and constitutes one end of the continuum explaining the role of qualitative research (Murphy & Dingwall, 2003).

While subtle realism also accepts the notion of an external reality, it differs from realism in that supporters of this approach acknowledge that observers of this reality are constrained by their “cultural-biological lens” through which their observations are made (Murphy & Dingwall, 2003, p. 13). Despite their recognition that different accounts of this external reality can co-exist, subtle realists are of the opinion that some observations and accounts are better than others, in that they are more valid by way of rigorous testing and evaluation.

Finally, on the other end of the continuum lies the relativist perspective, the followers of which contend that no-one can know or understand an external reality separate from his
or her personal biases and agendas, and that “nothing exists independently of the language and perspectives that bring phenomena into being” (Ballinger, 2006, p. 240). This approach to qualitative research clearly embraces the postmodern ontology discussed in Chapter 2 and advocates that qualitative research should focus on the ways in which “commonly shared worldviews are constructed and come to be accepted” (Ballinger, 2006, p. 240). Given my interest in the social discourses that accompany diagnostic labels and the way in which they shape the frames by which labelled individuals construct their realities, it seems logically consistent that a relativist approach to qualitative research be adopted here.

Regarding the nature of qualitative research, authors generally argue that qualitative research is holistic, naturalistic and inductive in nature (Durrheim, 2006; Murphy & Dingwall, 2003). The idea of qualitative research being naturalistic is that it is concerned with phenomena or experiences as they occur in real-life or everyday situations, without manipulation by the researcher.

Its holistic nature refers to the assumption that human experiences cannot be meaningfully understood by studying isolated variables or events, but rather by studying these events or phenomena as they occur within a wider and meaningful context (Durrheim, 2006). Murphy and Dingwall (2003) make a similar argument, stating that qualitative research embraces complexity by placing it at the centre of its enquiries, rather than controlling and simplifying it.
Finally, the inductive nature of qualitative research is expressed in its preoccupation with detailed and specific information gathering and analyses in an attempt to uncover themes or narratives regarding participants’ lived experiences (Durrheim, 2006). It therefore becomes apparent that qualitative research steers clear of rigidly determined research plans and opts for flexibility in engaging the data that emerge.

Finlay (2006, p. 3) uses the metaphor of a “research journey” to describe the nature of qualitative research and proposes that it is an endeavour aimed at exploring social realities, and therefore warns against the adoption of fixed ideas about the content or outcomes of the research. While preliminary ideas are set out to guide researchers in their projects, qualitative researchers seek to remain open to new leads, allowing the emerging data to guide their interpretations (Finlay, 2006; Murphy & Dingwall, 2003; Steward, 2006), rather than fitting the data into a predefined framework. It is therefore widely argued that qualitative research relies on inductive reasoning (Finlay, 2006), but Murphy and Dingwall (2003) argue that there is often an interplay involved between inductive and deductive reasoning in qualitative projects:

[Data analysis] occurs in parallel with data collection so that the researcher is continuously able to test, refine, and elaborate propositions developed in earlier stages of research. Theoretical statements are modified in the light of new observations [inductive element] and observations are sought to extend or modify existing or emerging theory [deductive element] (p. 23).
This then also highlights the central role that the researcher plays in constructing the knowledge obtained through qualitative enquiry. Murphy and Dingwall (2003), for instance, argue that any research account is inevitably an artful product, in that the author of such an account utilises various linguistic devices to promote the trustworthiness of a specific perspective or interpretation, because the author cannot escape from including and emphasising certain aspects of the vast observational field over others.

The researcher’s engagement in the research setting inevitably changes that setting, thereby making it impossible to inquire about people’s experiences as they occur naturally (Murphy & Dingwall, 2003). These authors, however, suggest that we can “seek to learn about their natural state from our examination of what changes have identifiably occurred in its transformation by our involvement” (p. 28).

By acknowledging our limitations, as outsiders, to instantaneously understand the settings we intend to study, Murphy and Dingwall (2003) suggest that qualitative researchers can avoid the pitfall of accepting its current organisation as absolute and through their engagement with the participants explore the question of “why things are one way rather than another” (p. 35). This tentative approach to the truth of a situation allows the researcher to formulate descriptions that represent the researcher’s take on the reality of that situation that might be different from the accepted version, and cannot be taken to be a reproduction of such a setting (Murphy & Dingwall, 2003).
Finlay (2006) further emphasises the importance of the nature of the relationship the researcher has with his or her participants. Not only is there a mutual perturbation between the researcher and his or her participants, but both are also informed by them being situated within wider socio-historical systems and culture, which has a bearing on the knowledge generated between them (Finlay, 2006). The qualitative researcher’s interest in the description of this relationship and the complex factors that bear on it, through a self-reflexive process, can yield important information on the way in which specific realities come to be (Murphy & Dingwall, 2003). These authors point out that while qualitative research focuses on description, such thick and detailed descriptions can themselves have explanatory power.

Bearing this in mind, there seems to be a good fit with the postmodern and social constructionist views adopted in this study, for a qualitative approach lends itself to the exploration of individuals’ unique experiences, highlighting the influence of context and thereby being open to the possibility of multiple realities. The focus on meanings in qualitative research also lends itself to the idea that realities are constructed by the use of language and the shared meanings attached to language. In keeping with the qualitative approach (and specifically the relativist position) that is adopted here, I wish to continuously explicate my own preconceptions of the research topic and invite the reader to consider the way in which these biases influence the findings of this study and to compare it to his or her own ideas on the topic as a means to evaluate the trustworthiness of the findings.
The research process

In conducting a thorough literature review, it emerged that very few research endeavours were devoted to the adaptive outcomes and experiences of individuals with diagnostic labels, and this lead me to identify a need for such a study. As a means of gathering data for the study, the interview technique was decided upon and suitable participants had to be identified and selected.

Selection of participants and sampling strategy

As the study focuses on people who have framed their diagnostic labels in ways that enhance their perception of self, a purposive sampling strategy was used in this study. Participants were identified via professional therapists to whom I provided criteria for the identification of suitable participants. I relied on these colleagues to contact suitable participants and to obtain permission from them to be contacted by me. The criteria for selecting suitable participants were identified as follows:

1) The participant must have been formally diagnosed by a health professional with a neurological, learning or psychiatric condition as listed in the Diagnostic and Statistical Manual of Mental Disorders, Fourth edition, Text Revision (DSM IV – TR). The important element in this criterion is that the participant has exhibited some behavioural difficulty in the past which was explained by a diagnostic label;
2) The participant must have accepted the diagnostic label to apply to him or her and must have shared this knowledge with others in his or her life;

3) The participant must have adapted to the condition and achieved some success in managing the labelled behaviour, as well as the stigma associated with the label.

Interviews of approximately one hour’s length with five participants were held to ensure that enough data were obtained within the limited timeframe for the study. Only three interviews with three participants were utilised in the analysis phase. The reason for this decision is twofold. Firstly, the results obtained from the three participants as presented were thought to yield a satisfactory account of the phenomenon under study; and secondly, the data obtained from the excluded interviews were deemed to be insufficient to serve the aim of this study.

The interview process

According to the proposed selection criteria for participants, individuals were identified and approached in a discrete fashion to ensure the preservation of their anonymity and integrity. Murphy and Dingwall (2003) describe the qualitative interview as “an opportunity to explore how informants themselves define the experiences and practices that are the object of the research” (p. 82). Therefore, efforts were made to avoid the imposition of predetermined categories, themes, etc. on research participants in a rigid
manner, and I was allowed the freedom to take new leads as they arose during the interview process.

Due to time constraints and the limited scope of this particular study, I found it useful to compile an interview schedule with identified themes, which were of interest to me, in order to guide the collection of data and to avoid deviating too far from the heart of the topic. It is important to remember that the interview schedule served as a beacon from which to explore different themes that emerged during the interviews, and far from being a standardised questionnaire, it served to remind me of the research aims in the event that the conversation got too far off track. Please refer to Appendix A for the full interview schedule.

It is important for the reader to take note that any conversation, even an interview, is inevitably situated in a specific social context, and whatever is communicated cannot be abstracted from the contextual constraints that bear on it (Murphy & Dingwall, 2003). The latter authors argue that participants’ communications will always be guided by their perceptions of what the researcher expects of them in the interview setting, and that such settings are invariably used by both the researcher and participants to present themselves as competent, reasonable individuals, whose actions are rational when explained from their perspectives. Such circular influences between researcher and participant are important aspects for the reader to consider when evaluating the credibility of the researcher’s interpretations.
However, in an attempt to minimise my directive influence, identified participants were presented with a general description of the aim and nature of the study. This was done in a manner that is non-directive; i.e. care was given not to influence the participants’ personal disclosures by presenting the aim in a specific direction. For example, by describing the aim of the study as an endeavour to explore individuals’ experiences of adapting to being formally diagnosed with a psychiatric condition and what they perceive the effects to have been on their outcomes in life relative to their diagnosis, participants were presumably provoked to think about their adaptive responses to their diagnostic labels without prescribing to them a right or wrong way of doing so.

**Data-analysis strategy**

As was discussed earlier, qualitative approaches choose to embrace the complexity of the settings or situations that are being studied. As the scope of a mini-thesis (in fact most research reports) is fairly limited, I was confronted with the task of selecting relevant data to the exclusion of other data to inform my interpretations, as an inclusion of everything is virtually impossible. This again raises the issue of researcher bias, as one might ask why certain data or interpretations are chosen and included above others. Based on the fact that the interpretations included represent my own view of the situation, which is but one of multiple ways to construe the data, Murphy and Dingwall’s (2003) three principles to consider when selecting what data to include in a representative research report were considered.
These include, firstly, that attention be given to extraordinary as well as routine or commonplace events; secondly, that sufficient contextual descriptions accompany the events that are included in order to allow for alternative interpretations; and thirdly, that exceptions or deviant events (i.e. those that do not fit the researcher’s proposed interpretations) are also included, should they manifest. By stating these principles explicitly, I hoped not only to remind myself to reflect on the degree to which my choices of what to include constitutes a representative account of the data, but also to encourage the reader to do the same.

**Discourse analysis**

Discourse analysis was used in this study as the method for data analysis due to its fit with the aim of the study. Ballinger and Cheek (2006, p. 201) mention that there is widespread confusion regarding “the purpose, ontology and methods” of discourse analysis, and argues that this stems mainly from the fact that discourse analysis is not a unified approach. In this regard, it is important to state explicitly that the discourse analysis utilised in this study draws on the postmodern ontology and seeks to describe the way discourses operate to construct certain views of reality to the exclusion or downplaying of alternative views.

In describing the contribution of Michel Foucault’s thinking to the understanding of discourses, Ballinger and Cheek (2006) mention that “Foucault posited the intimate association between power and knowledge … and explored this ‘power/knowledge’ link
using his concept of discourse” (p. 201). Specifically, Foucault saw power as an implicit consequence of the social and historical organisation of societies that saw certain discourses become prominent at certain times. Thus, according to Ballinger and Cheek (2003):

\[\text{Discursive frameworks order reality in a particular way, rendering it visible and understandable. At the same time, they constrain the production of understanding and knowledge that might offer alternative views of that reality} \] (p. 202).

Terre Blanche, Durrheim and Kelly (2006) make a similar observation and describe discourse analysis as “the act of showing how certain discourses are deployed to achieve particular effects in specific contexts” (p. 328). Fitting with the description of discourse analysis provided above, the aim was to identify and make explicit how the discourses, or ways of talking about each neurological, learning or psychiatric condition, leads to possibilities for participants to construct meaning from their experiences that serve to enhance positive perceptions of themselves as individuals living with a diagnostic label. To guide me in this quest, the following questions as formulated by Ballinger and Cheek (2006, p. 211) were considered:

- \textit{How are particular sorts of individuals, organisations and systems legitimised and strengthened through the operation of certain discourses?}
How do discourses work together to sustain particular realities and truths?

I therefore refrained from searching for truths in the transcribed texts from the participants’ interviews, but rather attempted to understand what happens (what reality is created) when they use language and discourses surrounding their diagnostic labels in a particular way and in a particular context.

To achieve the abovementioned goal, the directions put forward in Terre Blanche et al. (2006) were utilised. These authors admit that “there are no hard-and-fast methods for identifying discourses and analysing texts” (p. 330), but provides a multi-level approach for analysing the discourses operating in a text through immersion in and extracting oneself from the text and the culture that produced it. These contrasting positions allow a researcher to recognise the presence of various discourses by recognising the customs and ways of talking in that culture through his or her immersion in it. Also, by reflecting on the text and culture, he or she is able to gain awareness of the workings of discourses in achieving certain effects. The latter position is achieved through creating a critical distance between researcher and text (Terre Blanche et al., 2006, p. 331).

Identifying the effects of discourses

Ballinger and Cheek (2006) identify texts as the basic unit of analysis within discourse analysis, and argue that such texts are productive in nature, in that they convey
information that promotes specific constructions of reality. Texts can, therefore, not be assumed to be neutral ways of conveying information, but have specific, intended effects on its audience, which are conveyed by its assumptions that it will be understood (Ballinger & Cheek, 2006, Sarangi, 2000). Each participant’s text was, therefore, read through several times, after which it was analysed for various discourses and the effects these achieved or failed to achieve. While reading through the texts, I drew on my knowledge of and membership to Westernised South African culture as well as the mental health community and its customary ways of conversing, while also reflecting on the realities such ways of conversing create.

Binary oppositions, such as competent versus incompetent, normal versus crazy, were identified when present. Terre Blanche et al. (2006) highlight the importance of also attending to implicit binary oppositions, where one part of the opposition is explicitly stated and the other part is implied but silenced. Such silencing is illustrated when a psychologist says to a client that she is pleased to see that his complaining has subsided and that it is a sure sign that his depression is lifting. The implicit message is that his complaints are unpleasant and a sign of dysfunction, signalling the possible functioning of the ‘no news is good news’ discourse. Such binary oppositions can have the effect of appealing to the audience to align themselves to a particular side of the opposition (usually the side advocated in the text) and therefore have immense power in creating a particular reality and closing the possibilities for alternative realities (Terre Blanche et al., 2006).
Furthermore, recurrent phrases and metaphors that are used to convey participants’ experiences with and perceptions and expectations of their diagnostic labels were attended to, as such phrases colour the meanings of events and experiences in people’s lives (Terre Blanche et al, 2006). Terms such as ‘disorder’, ‘disability’ or ‘mental condition’ frame the meaning of the text in a particular way and present the subject of the text (in this case the participant) as ‘victim’, ‘innocent’, ‘helpless’, ‘sick’, and so on. The question, “What other terms could have been used to describe this person?” was kept in mind throughout the analysis of the results in order to reflect on the effects of such ‘victim’ (or any other) discourses.

A third consideration that was attended to when performing the discourse analysis was the subjects around whom the texts centred. As mentioned before, discourses have certain effects or powers on the audience and this holds for the subjects of the text as well. Terre Blanche et al. (2006) mention that discourses interact with one another to construct the subjects (participants) in particular ways. Depending on the micro context of the text, i.e. the text as contextualised in “conversation and debate” (Terre Blanche et al., 2006, p. 337), subjects and their actions can be construed as possessing purpose (Van Leeuwen, 2000), i.e. as being ‘helpless’, ‘voiceless’, ‘victims of their circumstances’, or ‘empowered victors’. Therefore, each interview was scrutinised in order to gain an understanding of the way in which the discourses operating in them interact to construct realities of empowered people with options for ‘better’ outcomes within particular contexts.
As is evident from the above discussion, context plays a major role in discourse analysis. Terre Blanche et al. (2006) suggest that discourse analysis should place texts into a micro context as well as a macro context. The former refers to context as created by the interactive nature of conversations, where individuals open up and close certain avenues of conversation through their mutual responses to what the other person brought to the table. Thus certain possibilities (also realities) are promoted or restricted by the flow of the conversation (Terre Blanche et al., 2006). Similarly, Ballinger and Cheek (2006) describe how the tone and connotations of particular words have *performatives* in that such words convey messages about the implicit and expected reaction that the text seeks to illicit from its audience.

The macro context refers to the broader setting of social practices, ideologies, norms and conventions within which conversations take place. The cultural practices and norms of a society prescribe the types of conversations that are appropriate in whichever setting (Terre Blanche, et al., 2006). For example, in a Westernised setting it is considered wise to follow the advice of doctors or psychologists when you experience physical or interpersonal problems, and their opinions on the possible outcomes (prognosis) of the problem are often taken as gospel.

Terre Blanche et al. (2006) propose that “[a] discourse seems to have a life across specific contexts. Thus, discourses are inflected with nuances of the particular institution

*Attending to context*
in which they are being used’ (p. 338). In accordance with this idea, Ballinger and Cheek (2006), propose that discourse analysis, by principle, also focuses on “how particular texts are indicative of wider cultural understanding and ways of sense making” (p. 204).

Consequently, attention was also given to the different means by which discourses work in different institutional contexts to inform the realities of participants as adapted individuals. It was assumed then that participants’ experiences of their involvement in and interactions with different macro settings, such as family, health care settings, religious institutions and the like, interrelate to colour their realities as labelled individuals with certain outcomes.

Therefore, an attempt was made to understand participants’ constructions of their identities in terms of the interactions of the discourses with one another in the context of conversations with others, as well as the meanings these discourses carry in the macro context of institutions and culture.

**The researcher as co-constructor**

The last consideration in the discourse-analysis process that was attended to involves a researcher’s role in co-constructing the realities of participants through his or her observations, descriptions and involvement with participants. According to Terre Blanche et al. (2006), a discourse analyst plays a crucial part in constructing the realities of
participants by means of the ways in which he or she punctuates their texts and analyses them, which also has certain effects and contexts, as this interaction between the analyst and the participants’ texts bring about a new text.

Specifically, my wish was to explore the adaptive outcomes of participants with diagnostic labels, and thus analysed their texts according to this goal. This in itself had certain effects, as a researcher (who brings his or her own views, understandings and ways of relating) becomes an active participant in the construction of participants’ realities.

**Trustworthiness and credibility of the study**

While I have attempted, throughout my discussion of the various phases of the study, to promote the trustworthiness and credibility of the research through open and transparent self-reflection and fair representation of different views, I realise that there is no method to guarantee the quality of this research endeavour. Therefore, the reader is explicitly invited to continuously engage in the evaluative practice of my findings. In an attempt to promote further reflection on the trustworthiness of this research endeavour, I would like to offer what Ballinger (2006, p. 240) calls “considerations for evaluation” to aid in the evaluation of the quality of the findings.

The first of these considerations involves the *coherence* of a study (Ballinger, 2006). When referring to the coherence of a study, the reader is encouraged to consider to what
extent there is a fit between the various aspects of a study, including the aim of a study, the methods used to pursue this aim, the worldview that informs a researcher’s decisions regarding his or her study and the extent to which a researcher acknowledges his or her role in producing the findings.

The second consideration concerns the extent to which the reader can see evidence of systematic and responsible research conduct. Such evidence might be reflected in the degree to which a researcher has given thought to his or her impact on participants, given the way he or she presented himself or herself to them, as well as through the provision of fitting extracts that have been accurately transcribed, described and contextualised to clearly illustrate the researcher’s interpretations (Ballinger, 2006).

The third consideration deals with the degree to which a researcher’s interpretations are convincing and relevant (also known as plausibility). Apart from being compelling or interesting, Ballinger (2006) also recognises that research should contribute to the knowledge or understanding of the domain under enquiry.

Finally, the reader is also encouraged to consider whether a researcher has shown sufficient reflexivity, meaning that he or she has shown sensitivity to the role he or she plays in the research process and outcomes, and that this role is appropriately accounted for given his or her epistemological orientation (Ballinger, 2006).
Ethical considerations

As research in the field of social science often focuses on topics that require participants to disclose details of their personal and lived experiences, it holds the threat that participants can be disadvantaged through their participation in research studies. In this regard, Wassenaar (2006) states that

... [it could] be argued that in most social science research the burdens of the research are borne by the participants while the benefits accrue to the researcher, who gains degrees, publications, prestige, promotion, etc., while the circumstances of the research participants remain unchanged (p.68).

In order to avoid such exploitation of research participants, the philosophical principles of autonomy and respect, non-maleficence and beneficence that guide ethical research (Wassenaar, 2006) were applied in this study.

Autonomy and respect

The first principle of autonomy and respect proposes that research participants have the right to maintain personal agency during the research process, as reflected by their understanding that their involvement in any study is voluntary; that they can terminate
their involvement at any point during the research process; that they have full knowledge regarding the nature and purpose of the study; and that their identity and any information they share can remain confidential on their request (Wassenaar, 2006).

In accordance with the principle of autonomy, participants were informed verbally and in writing of their rights and responsibilities, should they choose to participate in the current study. This was formalised on an informed consent form signed by myself and each participant, in order to ensure that all ethical conditions have been adhered to. Please refer to Appendix B for a copy of the consent form.

**Non-maleficence**

Related to the principle of autonomy and respect, the second principle of non-maleficence requires that research participants be protected from any personal harm as a result of their participation in a study (Wassenaar, 2006). In order to protect participants from any emotional or relational harm that could result from the current study, efforts were made to put them at ease regarding the confidentiality of the information they shared.

In addition, given the nature of the topic, care was taken to avoid framing participants’ experiences in a way that could lead to them feeling debilitated or stigmatised. This was achieved by acknowledging and respecting participants’ strengths and capacities, rather than only focussing on their negative experiences. As a further precaution against
emotional harm, participants were provided with the contact details of a psychotherapy clinic, in the event that our conversations might evoke experiences that they wish to address with the help of a psychotherapist.

**Beneficence**

According to the principle of beneficence, researchers should make the necessary efforts to maximise the potential benefits to participants for their participation in a study (Wassenaar, 2006). The benefits that stem from research should also extend to larger segments of society. In order to adhere to the principle of beneficence, an attempt was made to provide a supportive and respectful context for participants to share their stories.

In addition, as mentioned above, my interactions with participants were aimed at striking a balance between eliciting information on their struggles and accentuating their strengths and capacities. In this regard, I believe participants benefited personally from our collaborative effort to reframe (in a positive way) their experiences with their diagnostic labels as interpersonal metaphors. These benefits can also be extended to larger segments of society, as the research offers a way for psychotherapists to utilise individuals’ existing diagnostic labels in a positive, non-stigmatising way in psychotherapy.
Conclusion

In this chapter the qualitative research design was described as a useful and appropriate approach for investigating the meaning-construction processes participants engage in to construct their identities as empowered individuals in relation to their diagnostic labels. The application of the qualitative techniques in relation to the sampling of suitable participants, as well as data gathering and analysis, was described. Specifically, discourse analysis was presented as the method of data analysis and its basic principles were explained in terms of its relevance to this study. Finally, my attempts to illustrate the trustworthiness and credibility of this study as well as its ethical foundations were clarified. With these tasks settled, the focus in Chapter 4 will turns to the presentation of the participants’ interview results as subjected to discursive analysis.
Chapter 4 – Presentation of Participants’ Interview Results

Having dealt with the guiding methods of the research endeavour, this chapter is dedicated to the analysis of the personal accounts of the individuals that participated in this study. I trust that it will be evident from the outset that I consider myself to be an active participant in the construction of the narrative realities that follow. Accordingly, my inquiries should be seen as invitations to participants to engage in the activity of defining their identities in various domains of functioning in general, and in terms of their respective diagnoses in particular. This implies my acceptance of the fluidity of participants’ identities in relation to whomever they converse with and which activity type they are performing.

Therefore, in my capacity as participant-researcher, I acknowledge that I have contributed to the definition of the discussions as interviews, which in turn enabled and constricted various possibilities of communicative performance. In light of this, I subjected my enquiries along with the responses of participants to the discursive analysis, and explicitly stated the activity type that is requested or performed, if it was indicated. The excerpts of interview data are often presented in a dialogical form with two or more speaker turns. This is done to illustrate the interactive and collaborative nature of the meaning-construction process between participants and myself. To facilitate cross-referencing to dialogical turns, each speaker turn have been numbered, and reference to a specific dialogical turn is indicated in the text as either “Turn 1”, “Turn 2”, etc.
Furthermore, the results are presented in the form of metaphoric narratives with different unfolding plots. This approach was opted for as it will hopefully inform the reader on how I thought about and made sense of participants’ stories. This should also draw attention to the subjective nature of my interpretations. I believe that metaphors provide rich reference points for making sense of abstract lived experiences, while avoiding the traps of objectifying such experiences as absolutes. The reader is therefore invited to consider alternative metaphorical narratives and plots, and the way in which this could impact on the interpretations offered.

**Parkinson’s: When there are three sides to a coin**

Tiaan, an Afrikaans-speaking white man, is a distinguished academic who at the age of 52 years has completed numerous degrees in various academic fields, and continues to expand on his already impressive scholarly achievements by applying himself to the field of psychology at present. In his own words, Tiaan describes himself as “a scholar of life” and this is evident in his definitions of life’s experiences and difficulties, and how he situates himself in them.

Tiaan was married for 24 years and has two children, both in their early adulthood. In December 2005 Tiaan was on holiday with his wife, and while out on a stroll along the beach, he noticed that his left foot’s sandal was dragging on the tar road. A while later he consulted his general practitioner, who referred him to a neurologist, and he was diagnosed with Parkinson’s disease. Tiaan describes his journey of coming to terms with Parkinson’s disease. Tiaan describes his journey of coming to terms with

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2 A pseudonym is used to protect the participant’s anonymity.
this news as a personal one, where his life as he knew it came to a grinding halt. Apart from the challenges to his perception of self, the diagnostic event also placed strain on his intimate relationships, as Tiaan and his wife subsequently divorced. Also, his relationships with his children changed, and he sees them less frequently than before his diagnosis.

Tiaan’s story of what followed is one of struggle and heartbreak, yet shimmers with courage and hope for new possibilities in his life. I now offer my account of his story by unpacking the discourses that we both contributed to the construction of his identity as a person living with Parkinson’s disease.

When disaster struck

It is said that the more something is coveted, the greater the experience of loss is when the object of one’s affection ceases to be. When we assume that our physical appearance and functioning comprise an integral part of our identities and how we relate to the world around us (Barlow & Durand, 2005), it follows that news of a disturbance in our agency to conduct our physical selves in our environments holds a threat to our identities. Following the diagnostic event where he appropriated the Parkinson’s label, Tiaan describes the impact this event had on him:

1) Researcher: And then, at this stage, the diagnosis that you, well, are diagnosed with?
2) Tiaan: Three years and a bit ago, I was diagnosed with Parkinson’s disease. Yes, we can talk a bit about it later on, but it was a bit of a shock because it is a physical thing. I had always been a physical person, and sport activities and working in the garden, and my body is very important to me. I looked after my body through all the years, I never played contact sports and ruined my body, I always exercised and took care of my body. So it was a big shock to hear that I have a degenerative illness, and uhm, I feel it in my body every day, that there is something that gnaws at it, that there is something which is not right.

Firstly, it should be noted that the dialogue takes the form of an inquiry or interrogation, i.e. the interaction is defined as one where I request information and Tiaan provides information according to his discretion and to the best of his ability. The first of my questions in this excerpt contains certain assumptions, the most important of which pertains to agency.

By framing my question in the passive voice, Tiaan is presented to have been a passive agent, or even the object of the actions of another unknown agent. Tiaan’s response to this question follows suit and he also frames himself as a passive recipient of the diagnostic label. This has the effect of defining Tiaan as having lacked personal agency at the time of the diagnosis, and thus the diagnosis is presented as an infliction, something that happened to him over which he had no control. This definition of him as lacking
control over what happened to him is further strengthened by the shock he experienced after the event. In essence, Tiaan attributes his shock to the fact that he himself took several preventive measures, albeit unknowingly, over the years, but yet this did not enable him to avoid Parkinson’s disease.

The effect created by this preventive discourse is that it resolves Tiaan of any blame or responsibility for this infliction, while also painting Parkinson’s as an invincible force, something that could not be prevented. Consequently, the impact and intensity of the disturbing news is escalated, thereby inflating the challenges and struggles he has yet to talk about.

In the context of the bigger discussion (i.e. one defined as a research interview centring on individuals’ adaptation to diagnostic labels), the implicit request made to Tiaan is to engage in an activity of defining himself in terms of how he adapted to a presumably negative event. Therefore, the request demands that he relate his identity and adjustment to the negative diagnostic event. The positive-negative binary opposition thus operates to inflate the struggles and challenges, in order to inflate the impressiveness of his adjustments to his struggles.

It is also interesting to note how the illness itself is presented. Tiaan first defines Parkinson’s as “a physical thing”, thereby adding specificity and vagueness in terms of the locus of responsibility to the definition at the same time. Two lines later, he defines Parkinson’s as a “degenerative illness”, which is more specific in terms of the
consequences that it entails, but now lacks specificity in terms of what is affected. The first definition of Parkinson’s as a “physical thing” is used to highlight his positive attributes in the past, i.e. being active, by relating it to the physical side of Parkinson’s. The second definition as a “degenerative illness” highlights the continuation of his battle with Parkinson’s, which is represented as a parasitic agent that nibbles at his body and causes continual decline in physical functioning. The third definition that he offers, frames Parkinson’s as a “neurological thing”, something that is in the brain.

Specifically, Tiaan later expresses his disbelief that the physical symptoms represented a neurological disease: “…but I never thought that it was a neurological thing…”. These various definitions of Parkinson’s create the effect of a gradual escalation of the seriousness of his condition. Notice also that there is a decline in the degree of personal responsibility associated with each definition. The first definition, Parkinson’s as a “physical thing” could entail that responsibility for the effects of the condition resides with him. Parkinson’s as a “degenerative illness” implies that the condition is an infliction, whereas Parkinson’s as a “neurological thing” implies that all the symptoms and the origin of the condition are due to the complex neurological system, which is presented to be an agent distinct from Tiaan.

The preventive discourse then draws on cultural values of personal control, and opposing this discourse with the fact that he developed Parkinson’s disease, Tiaan is presented as someone who complied with the values of personal control. His developing Parkinson’s, on the other hand, is presented as a fatalistic event, one that could not be prevented. The
fate of his situation maximises the adversity which he is faced with, and lays the ground for a construction of himself as one who faces this impossible situation head-on. In effect, Tiaan’s situation demands a difficult choice to make … to either adapt or die.

What the idea of adapt or die advocates is the necessity of organisms, including humans, to adjust their relative positions in their ever-changing environments in order to avoid catastrophe. In the preceding sentence, “relative positions” can refer to various levels of functioning, including our physical, mental, relational and emotional responses to changes in the environment. In the following dialogue, Tiaan describes his response to the first indications that something was up, as well as his struggles with what it will hold for him in the future:

1) Researcher: ... so I’m just wondering in terms of when you saw your foot dragging, what came up for you in terms of what it might entail for you?

2) Tiaan: I didn’t really grasp it at that stage, because, but I think a diagnosis, if one gives a name to a condition and you name a thing, then the condition gets personified, it gets internalised. At that stage I thought it was just fatigue, maybe a physical fatigue, it’s year-end, December month, on holiday, and now I’m walking strange, a bit off balance. Uhm, I really didn’t want to think about it. Like I said, only ten months later did I have the courage to do something about it.
In this excerpt of our discussion, the initial question frames the presenting symptom, i.e. his foot that was dragging, as potentially holding significant implications for his future outcomes. Implicit in this framing of the question is the assumption that the symptom acted as a sign of things to come, and that these are significant things in terms of how he defined himself in relation to the symptom. In effect, my enquiry can be seen as requesting a definition of self in terms of future outcomes.

Tiaan’s response to my invitation indicates that the significance of what he was about to face eluded him initially, and that the significance of the symptom as a sign only became a reality to him after it was given a name. His initial denial of the importance of the symptom as a signal and his rationalisation of what it might be points to the multitude of possibilities that are available before the symptom was framed as Parkinson’s disease. Effectively, the benign nature of the interpretation of the symptom as merely fatigue is contrasted with the seriousness of the official interpretation of it as Parkinson’s and the narrowing of possibilities, which brings into salience the intensity of the blow he eventually was dealt. The struggle and courage that he had to showcase is further emphasised by his admission of the time he needed to prepare himself for the revelation of the ‘truth’. In effect, the revelation of the ‘truth’ of his situation is framed as an ordeal that required excessive preparation and courage to adjust to.

I proceeded to ask Tiaan to clarify his definitions of the concepts “personify” and “internalise” as used in the preceding excerpt:
1) Researcher: What do you mean when you say personify and internalise?

2) Tiaan: I think the moment one is diagnosed with an illness, you must do something with the label that is given to you ... Then you start reading about it and then begin looking at the symptoms, and then all of a sudden you start seeing symptoms that are described in the literature. So my biggest struggle in the beginning was, “Am I the illness, or is the illness in me? What is the relationship between me and the diagnosis?” I think the internalising or the personifying thereof comes as a first shock: “I am Parkinson’s, I am cancer, I am diabetes”. And to get over that thing, I think it is one of the biggest steps one should make, and that comes with time, it comes through reflection, it comes through knowledge acquisition. My first reaction was: “Oh, I’ll outlive this thing, I shall carry on with my movements, my activities”. I still went horse riding, drove my motorcycle ... and all of a sudden these things started taking their toll.

Here Tiaan describes a process of adaptation that he frames as an imperative, indicated by the framing “... must do something ...”. Furthermore, this process is described as something that applies to all individuals, which presents Tiaan as an authority figure on the steps needed to make this transition, based on his personal experience with this process. He then explicitly defines his “biggest struggle” in terms of differentiating and possibly integrating his identity and the Parkinson’s condition. Already, he defines
himself as having made significant progress in this regard, as he frames this struggle as an initial one, i.e. “in the beginning”.

It is interesting to note the implications of the adapt or die discourse, as it presents different and seemingly contradictory levels of logic. Firstly it implies that a choice needs to be made, but it also imposes a necessity to adapt, as one cannot exist without having adapted. Tiaan seems to utilise these levels of logic in legitimising his choice of not fighting his condition at present, as in the past he was subjected to this necessary process of adaptation. In other words, he went through the motions of challenging the disorder and carrying on living through his fighting spirit, etc., which is framed as something that is a natural response to such a condition.

However, Tiaan states the following:

So I wanted to challenge the diagnosis, but it became too much. Then I needed to enter a different phase of my understanding of the situation, meaning that it would require a new lifestyle from me.

His realisation that he needed to adapt or die then demanded a more difficult challenge from him, one that required a difficult choice. This choice was to sacrifice his old lifestyle, which he experienced as very fulfilling, and settle into a new one that fits with his condition. Although this choice was demanded from him by his condition, he was the one who entered a different phase of his “understanding of the situation”, which allows
Tiaan to claim and incorporate the culturally valued characteristics such as maturity and perseverance into his definition of self.

**The two sides of a coin: The false dilemma**

After his confrontation with the official interpretation of his physical difficulties as being indicative of Parkinson’s, Tiaan’s efforts to integrate this new information into his definition of self in relation to his environment presented him with various images of the effects and possibilities associated with Parkinson’s disease. Given his age at which he was diagnosed and the stereotypes associated with the condition, Tiaan describes the dissonance that he was faced with in integrating his impressions of Parkinson’s into his definition of his future self:

*They [the neurologists] both emphasised that I am still very young for this condition, which naturally was a big shock for me, because it is basically an old person’s illness of walking slow, walking with a crooked back, being slightly off balance, slow to stand up out of your chair, and to visualise such a picture for myself was very traumatic for me, that I can now become like an old person after a life of activity, and outdoors, and walking, and camping, and being busy.*

Here Tiaan describes one of the available images that significantly restricts the possibilities to adversely negative implications of having Parkinson’s. In a culture that
places high value on youth and physical vitality, the notion of aging has become imbued with negative connotations. Although there are also some culturally valued aspects, such as wisdom and maturity, that are associated with old age, Tiaan does not include this in his visualisation of himself as becoming like “an old person”. The contrast of his relatively young age against the drastic representation of an old person’s illness juxtaposes the stereotyped image of Parkinson’s with his personal image of self. Effectively, the idea emerges that he is somehow different from the stereotypical image, and that this would call for a different or altered image of the condition as it pertains to him.

Tiaan expands on his need for a unique image of his situation in response to my enquiry about his previous encounters with images of Parkinson’s:

1) *Researcher*: Did you have any previous ideas about ... or have you heard from Parkinson’s before you ...?

2) *Tiaan*: My knowledge of Parkinson’s was an old man in our church ... and he shivered terribly, his head shivered terribly, and his hands shivered, so it was the only image I had of Parkinson’s. I also heard of Michael J. Fox, there lay a book of his next to you, who also has the condition under wraps. Uhm, from the beginning I was scared to read about the condition. I took out articles from the library, but after having paged through it, I saw that it wasn’t written for me, it was
written for people in an old age home, people who can’t chew their food properly, who mess on their chests, and I said this is not me ...

Here it is clear that Tiaan’s emphatic rejection of the stereotyped image of people with Parkinson’s and his refusal to associate himself with such images serve to highlight his differences in relation to the typical case. By exclaiming his individuality and uniqueness as a relatively young person with Parkinson’s, Tiaan attributes qualities to his identity that set him apart from the typical case, and in effect the possibility emerges that he might have a fighting chance to obtain different outcomes. Later in our discussion, Tiaan explicitly acknowledges his faith in his own distinctive chances:

... what I held onto is that it is a unique situation, and that I look different from an old man in an old age home that messes on his chest because he can’t keep his food in his mouth.

He also expresses his need to form his unique image of his condition in response to other people’s tellings about Parkinson’s:

So I got differing images of the illness, people who died as a result, people who became passive, became totally immobile as a result, and then other people who just carried on with their lives ... Yes differing images came up for me, from somewhere I had to create my own image of this thing.
An important distinction between the hopeful and negative images of Parkinson’s that Tiaan describes is the amount of detail he utilises in the respective descriptions. When describing the negative images he is faced with, Tiaan employs highly specific and visually descriptive words with the effect of presenting an absolute and narrow definition of Parkinson’s. However, because he does not fit the mould of these negative images, the absolute and narrow outcomes need not apply to him. Instead he chooses to buy into more hopeful images of the condition, which he does not describe in any specificity and does not imbue with absolute terms. As a result, these hopeful images allow for more flexible outcomes and possibilities for his future.

**Head in the ground**

In evolutionary discourse it is advocated that organisms, when confronted with an extreme and threatening situation, have essentially two options, either to fight or to flee. (Geen, 1995) However, even though individuals often buy into such dichotomies, it usually appears after some closer inspection that such dilemmas invariably contain certain falsehoods.

Being confronted with a severely threatening revelation pertaining to his definition of self, Tiaan describes a similar behavioural dilemma he was faced with and the way in which it influenced his initial attitude towards his condition:
1) Researcher: How did he [the neurologist] explain it to you, when he told you it is Parkinson’s? What was his explanation about what you can expect and what Parkinson’s is, and that type of thing?

2) Tiaan: I can’t really remember Nico, whether he gave me a terrible lecture about the situation, I was, I was in such a trans, I was so anxious, I was totally freaked out that I can’t remember ...

He continues after discussing the images of Parkinson’s he found from articles in the library:

3) Tiaan: Yes, and then also a piece, a piece of denial of the situation, and what I held on to is that it is a unique situation, and that I look different from an old man in an old age home ... I didn’t see myself in that picture. I decided that I am going to give this thing a go, I am going to fight it ...

In Turn 1 in the preceding excerpt, I ask Tiaan to reflect on the information he was given by the expert on Parkinson’s regarding the implications of being diagnosed with Parkinson’s. Implicitly, I define the expert as a knowledge bearer on the condition, whose responsibility it was to impart information on the receiver, Tiaan. The framing of my question, however, does not imply a unidirectional flow of information with Tiaan as a passive receiver of knowledge.
Rather, in framing my question as “What was his explanation …?” the emerging definition of the interaction becomes a complementary one, where the expert’s responsibility is to impart his subjective explanation and Tiaan has the responsibility to do something with the information he receives. This definition of their interaction is not explicitly stated in my question, but is inferred from the context of their interaction, i.e. an interaction that includes an expert who informs; a topic (Parkinson’s) that is discussed; Tiaan who is being informed on the topic; and a culturally negotiated agreement on the script of such a type of interaction. Tiaan’s response to this question then relies on the coherence of my text.

In his response, i.e. Turn 2, Tiaan accepts and responds to my definition of his interaction with the neurologist by confirming the expert’s role as ‘lecturer’, yet legitimises his rejection of his own role as information recipient in the interaction. He achieves this legitimation by highlighting the stressful nature of the situation and describing his reaction as one of being in a “trans”. It can thus be argued that he draws on the flight contingency of the fight or flight discourse to explain his reaction to the devastating news he received. In effect, in a culture where taking a fighting stance is valued, the context that is being constructed by Tiaan allows his audience, including me, to develop sympathy for his situation and his flight reaction.

His flight reaction is carried over to his elaboration on his emerging attitude in Turn 3, albeit in a modified form. His explicit acknowledgement of his denial of the situation strengthens the sympathetic effect on his audience, as it communicates self-awareness of
his reactions. Furthermore, in his explicit acknowledgement of his denial, Tiaan achieves a remarkable transformation of the flight contingency into a narrative of survival and holding on. Although it would have been easier to give up and cower away, Tiaan states that he found something that could be “held on to”, and his individuality became a source of strength to stand up against being a victim of his diagnosis. His vivid description of an old man in an old age home creates a pitiful mood in the audience for such a helpless person, and by highlighting his own difference, Tiaan implies his refusal to be another victim. His initial reaction of fleeing is therefore transformed into a conscious decision to challenge the supposed fate that awaits him.

While those who make pledges are admired for bravery, those who stick blindly to them are fools for pride and engineers of their own ridicule. The truth of this statement is besides the point, but in it I recognise a struggle that I seem to share with Tiaan and possibly many others. Where does one draw the line between committing to an oath and following it to your grave? Tiaan’s story makes reference to this question when he tells of his revolt against becoming a victim of the fateful implications of Parkinson’s:

... There was a time in the recent past that I faked, faked walking up straight, faked being my old self, acting like I’m still what I was, walking nice and strong, but I can’t fake it anymore, and I’m making peace with it now, this is now a new phase that I’m entering. So if I’m a bit unsteady when I quickly have to turn around ... or if I have to walk with a walking
stick ... then I do it. This is how I am, and this is my image, my locus of control is still inside me.

Here Tiaan offers an account of a phase of revolt or resistance against the physical implications of Parkinson’s. His repetitive use of the word “fake” in reference to his way of walking and being indicates the profound impact his physical symptoms had on his identity, so much so that he felt he needed to pretend to be what he always saw himself to be. Although it is not explicitly stated, there is a strong interpersonal aspect to his faking, as the word “acting” implies a performance to an audience. In another part of the discussion, Tiaan makes explicit mention of this interpersonal aspect when he says:

... and I wondered what do they see in me ... and then one tries to overcompensate for it, walk more up straight, appear more robust, and when you speak to people, not to put up a sorrowful voice.

Tiaan’s reference to his trying to portray the image of someone walking “nice and strong” immediately evokes the opposing image of someone who walks with a weak posture. For me this binary opposition then refers to his attempts to avoid inducing pity in others, because in a Western culture pity is invariably reserved for the weak and victimised and being at the receiving end of it does not bode well for one’s perception of self. In this sense, his attempts at faking his old self can be seen as a revolt against assuming the victim role and its implications of helplessness and lack of personal agency.
As Tiaan acknowledges, however, his situation was such that he could not keep up with the faking any longer. When considering the dilemma he found himself in, i.e. the fight or flight contingency, it would seem that his inability to fight through faking implies a necessity for falling back into the victim role. It seems, however, that the fight or flight discourse and the rebel-victim dilemma it presents enable Tiaan to forge a middle road, a possibility that was ‘hidden’ from plain sight as a dilemma does not allow for its existence.

**A third side to the coin: An act of balance**

As is often the case, dilemmas tend to represent oversimplified accounts of situations and eventually turn out to be false. For a moment I return to the same excerpt discussed above:

... *There was a time in the recent past that I faked, faked walking up straight, faked being my old self, acting like I’m still what I was, walking nice and strong, but I can’t fake it anymore, and I’m making peace with it now, this is now a new phase that I’m entering. So if I’m a bit unsteady when I quickly have to turn around ... or if I have to walk with a walking stick ... then I do it. This is how I am, and this is my image, my locus of control is still inside me.*
Tiaan’s acknowledgement that he “can’t fake it anymore” seemingly presents a state of affairs where he has given up fighting his condition. Taking a closer look at the way he frames his giving up control, to me it does not imply that it was imposed through defeat, but rather represents an acceptance of his situation. This acceptance is indicated by his statement: “I’m making peace with it now … if I have to walk with a walking stick … then I do it”. The structure of the sentence above places Tiaan at the subject level performing an activity (i.e. making peace), and he is portrayed as being successful in his endeavour. Although his choice to make peace is indicated as a necessity, he still retains control over the decision, as he is in the subject position “then I do it”. The framing of the text in this passage effectively presents Tiaan as an active agent who arrives at a satisfactory state of affairs through a conscious choice for which he takes responsibility.

This middle ground discourse is elaborated on by Tiaan as he describes how handing over control relates to his self-esteem and identity:

1) Tiaan: It is not an easy process, because I mowed the lawn all these years and was very physical ... But I think that is why it’s easier for older people to have Parkinson’s, because they can’t do anything physical anymore, so the Parkinson’s does not contribute to their self-perception, nor to their understanding of self, it is just the aging. But I am not at that age yet, so it took a certain process to come to a point where I hand over, hand over control.
Further on in the dialogue:

2) Researcher: ... How did you draw the line between having to rely on people versus that you become totally helpless almost, understand, that you still retain that sense of control?

3) Tiaan: The handing over of control is an important theme in this experience of mine ... I don’t mind anymore that I can’t mow the lawn. I hand over the control to someone who is able to do it ... But on the other hand I must tell you, it’s not a total abdication, because total abdication and total forsaking of your responsibilities would make a person helpless. I still have a responsibility towards myself ... I only do it in another way, I only do it within the restrictions, within the parameters that are set for me now. Helpless, no, total control, also not, it’s something in between.

Notice in Turn 1 above how Tiaan frames his struggle to wed the stereotypes associated with his Parkinson’s diagnosis into a harmonious perception of self. Once again he draws on the metaphor of aging and the stereotyped image of Parkinson’s as a condition for “older people” to highlight the dissonance that exists in his conception of self. The juncture between the implications of being old and that of having Parkinson’s is utilised and juxtaposed against his relatively young age in order to illustrate the unnatural sacrifice he has to make. In essence, he demonstrates the dilemma he faces: He cannot continue with his life as he did in the past, but has not reached old age yet, and so simply
giving in to the implications of Parkinson’s becomes a troublesome factor for his self-esteem. Being caught between a rock and a hard place then serves to implicitly legitimise his handing over control, as it resulted from a necessary process due to his difficult position. Therefore, Tiaan can distance himself from any notions that his handing over control is motivated by learned helplessness or his seeking secondary gain.

In Turn 2 above, my enquiry makes explicit the potential interpretations of handing over control as that of choosing to be helpless versus that of accepting one’s reliance on others. My framing of the question implies that I assume that he has drawn such a line, and also that I accept drawing that line and choosing reliance above helplessness as a preferred alternative. In this sense, I invite Tiaan to share his modus operandi in drawing this line, yet should he not have achieved this preferred goal, my question with all its assumptions would make it hard for him to admit it. It should be noted, though, that my enquiry did not emanate out of a vacuum, but resulted from the mutual process of making meaning out of our discussion thus far. Therefore, my question can be seen as another step in the continual process of negotiating the meanings of Tiaan’s experiences.

It is seen in Turn 3 above that Tiaan accepts my invitation to explicitly define his position in the dichotomy I presented him with. Tiaan’s admission that he does not mind anymore about giving up control indicates that the argument contained in the control dichotomy is no longer relevant, at least to him. In other words, the message that he communicates is that he has reached a meta-level of understanding his situation, which transcends the question of retaining or losing control.
In deciding to accept his situation and hand over the control he forged through his faking, Tiaan retains control on a meta-level through a process known as *dramaturgical legitimation*, which is based on the honesty and sincerity of the speaker’s actions. In this sense, the dilemma of retaining or losing control clears up and he no longer stands at a fork in the road, forced to choose between being either rebel or victim. By transcending the control dilemma, a new option became available, one of choosing to accept his condition and hand over control. By drawing on this middle-ground discourse, he retains his personal agency, thereby retaining control, as one needs some control to hand over control. Thus Tiaan rightly states: “... my locus of control is still inside me”.

**Then and now: Taking stock**

When engaging in reflections on one’s past, it often happens that one realises in retrospect that things just seemed to work out for the best. Whether one chooses to call it fate or coincidence, what is really intriguing about such epiphanies are the meanings and the sense of connectedness to something greater than oneself that these realisations can provide. In essence, I would offer that *fate explanations or discourses* serve as reassurances that our experiences are somehow linked together and build on each other as fragments of a purposeful life.

In a similar trend, Tiaan’s reflections on his life prior to and after his diagnosis with Parkinson’s lend a similar functionality to his experiences with his condition:
1) Researcher: With this diagnosis, you know there are all these negative connotations attached to it and the impact it can have on your life and future. Would you say that you discovered any new qualities of yourself ... as a result of this diagnosis ...

2) Tiaan: Two things occur to me. Firstly, through the years and through mercy I have built and maintained good relationships with people. So when I needed them, every one of them was there, hundreds of them. Colleagues, family, friends, in-laws, neighbours, friends of my children, so my support group was in place ... The other aspect that I discovered in myself is that my life up to now was so disciplined, physically and psychologically, intellectually and cognitively, so disciplined that I can now fall back on that sort of discipline ... Every marathon that I ran, every hiking trail that I walked, prepared me for what I now [...], for the qualities and attributes that I need now in order to go forward. Pushing through, I know about pushing through.

In Turn 1 above I utilise the negative side of a binary opposition pertaining to the outcomes of Parkinson’s to assume the potential existence of positive outcomes that might have resulted as a function of the way in which Tiaan frames his experiences with Parkinson’s in defining his identity. In effect, Tiaan is invited to consider the possibility of such positive spin-offs in terms of the way in which he thinks about himself. Since our discussion is a reflective one, the reality of such positive spin-offs does not exist in the events themselves, but is created post facto, through the activity of reflecting.
Tiaan’s response in Turn 2 utilises reference points in the past and connects them to situations in the present. In this sense an arch of meaning is formed that connects events and experiences from his past in a purposeful way to his experiences and needs in the present. Tiaan achieves this creation of purpose by utilising attributive words or purpose links, thereby connecting certain purposeful actions to the purpose itself.

For instance, consider the statement: “Every marathon that I ran … prepared me for what I now […] for the qualities and attributes that I need now in order to go forward”. The purposeful action would be “Every marathon that I ran”, whereas the purpose would be “prepar[ing] me … to go forward”; and the purpose link which ties the past and present together is “in order to”. Therefore Tiaan draws on the fate discourse to frame his disciplined nature in the past as having a preparatory function for his present dealings with Parkinson’s.

It should further be noted that in this preparatory framing of purpose, Tiaan becomes the sole agent in which the purposeful action and the purpose itself resides, thereby situating power and personal agency fully inside himself. Therefore, Tiaan is framed as the agent who (unknowingly) engaged in the purposeful action in the past, and in doing so has allowed the purpose (i.e. preparing himself to move forward) to be achieved at present.

This notion of purpose seems to reverberate through many of Tiaan’s accounts of the positive lessons he has learned through his struggles with Parkinson’s:
The positive thing I take from it is the [...], luckily I read the book of Eckhard Toll, “The Power of Now”. You learn to live in the present ...

The power of now, to live now, and the quality of life definitely increases when one is here, and not there or in the past ...

And again in his account of how he benefited spiritually from his experience with Parkinson’s:

... uhm, a closer contact with the spirit world, call it God, call it anything, a connectedness to all sides, horizontally, vertically, laterally. A bigger connectedness, I feel more human than in the old days when I used to chase after, I don’t know what. I feel more whole, I feel more fulfilled, I feel more rooted, but not without people.

It seems clear from these accounts that Tiaan ascribes definite purpose and meaning to his struggles with Parkinson’s. Whether these purposes are determined by fate or constructed as stories after the fact seems unimportant. What seems to be clear is that the fate discourse provides him with a sense that his struggles were not without purpose.

Conclusion

By drawing on the various discourses described above, Tiaan is able to find meaning in the devastating condition he is faced with. Specifically, he refrains from buying into any
rigid conceptions of Parkinson’s, thereby individuating himself from the ‘typical case’ and constructing himself as a person with options to pave his unique way forward. In this sense, he embraces the responsibility to lead a purposeful and fulfilling life with the circumstances he has been handed.

Although Tiaan’s story is largely focussed on his personal struggles with adapting to his diagnostic label and constructing meaning out of these struggles, he seems to rely heavily on an interpersonal framing of his diagnostic label to achieve this. This is seen in his juxtaposition of himself as a person with Parkinson’s versus the ‘typical case’ as reflected in the images he offers of elderly people in an old age home.

Such an interpersonal framing also finds expression in his struggle to maintain his independence versus having to rely on the help of significant others. In this sense then, his diagnostic label was framed as an interpersonal metaphor for his need to find a midway between total independence from others versus helplessness. In this sense, Tiaan was able to construct a new role definition for himself in relation to others, one where he is a delegator of responsibilities and still maintains control and responsibility for his reliance on others.

Now that Tiaan’s story has been subjected to a thorough analysis and discussed in detail, it is an appropriate point to introduce Stefan, the next participant, who has been on a lifelong journey with his dyslexia label.
Dyslexia: To bring about a revolution

Stefan, an Afrikaans-speaking, white man, is currently 41 years old and works in the field of mechanical engineering. In 1995 he graduated with a BTech degree in Mechanical Engineering at a local university of technology and has achieved remarkable success in his career. He recently started working for a new company to broaden his horizons. Stefan, who describes himself as a thinker and a workaholic, reports facing big challenges in his occupational settings due to his difficulties with reading and writing. It was early in primary school when his parents sent him for a psychometric evaluation due to his difficulties with spelling, and during his school career he appropriated the diagnosis of dyslexia.

Stefan reports that he has been happily married for 18 years now and that he has two daughters in primary school and a son of three years old. Stefan admits that he was not always intensely involved with his children, but when his son was born with Down’s syndrome, he claims to have had a change of heart and made his family his first priority.

His story is one of an immense and lifelong struggle for liberation and freedom from the shackles imposed by the bourgeois ideals of the academic and professional systems that, according to him, still exist to some extent today. I have therefore come to think of Stefan as a revolutionary, a freethinker and a hero of change.

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3 A pseudonym is used to protect the participant’s anonymity.
Equality, privilege and injustice

It is generally accepted in Western cultures that difficult times call for a hero to stand up tall and straight and bravely face the perils of injustice that leave others trembling. Few heroes of revolution have claimed their glorious titles without the aid of a context reeking of bitter political, economic or personal struggle. Real-life and fictional figures such as Nelson Mandela, Tokyo Sexwale and Batman are cases in point. In the case of Stefan, the injustice discourse seems to play a fundamental role in creating a context in which his liberation from these personal and interpersonal struggles, which are attributed to dyslexia, can be highlighted. Stefan, being the agent who is confronted with these injustices, is presented as an individual who has to battle against various obstacles in his fight for deliverance from the stigma associated with dyslexia. An example of the injustice discourse and its relation to the equality and privilege discourses is put forward in the following extract:

1) Researcher: So at which stage of your life did you become aware of that label, the dyslexia, that you have it?

2) Stefan: Man, it started already in Standard 1 dreadfully, where I stood in the stupid crowd and I knew clear and well that Friday the spelling test is done and it is darkness for me, I don’t know how I’m going to pass. Then you still get a hiding if you failed, know so it was just totally negative for me, the whole thing ... Standard 3 I suddenly had to attend extra reading lessons during break time, where the English
teacher got her teacher’s pets and I now have to sit with them and read, because my reading ability was, and it was terribly destructive for me, know a fellow pupil as old as me now has to teach me how to read ... or I have to read in front of them ... that was teachers, but she was old, she came from the old school and the old method. So I can’t blame her, I mean it’s just how they saw things back then. But I can tell you straight now, it’s the biggest mistake that you can make, or at least for me it was totally wrong. And it already gave me a label, I had the spelling label already, then I realised I have to get the reading label against me as well ...

Here Stefan’s doubt in his own academic abilities, coupled with the negative labels others attached to him, is presented as a core difficulty that adversely affected his self-esteem and perception of self. Notice that my question in Turn 1 is a request for him to provide a punctuated moment in history when he became aware specifically of the dyslexia label and its bearing on him. Through my question I define our discursive interaction as an informative one, i.e. where Stefan is expected to provide historical-factual information regarding the time at which his ‘discovery’ of the dyslexia label occurred.

Stefan’s response in Turn 2 does not provide the requested information, but instead he gives a reflective response on his negative experiences as a child. In framing his response as a reflective one, Stefan refrains from providing factual data, but rather focuses on the interpersonal interactions that impacted on his perception of self. Being suddenly pushed
into extra reading lessons evokes the image that Stefan was ill-informed and therefore ill-prepared for the situation he was about to face at school and he is therefore presented as having been at the mercy of an unknown oppressive power with little consideration for his feelings and right to dignity.

The humiliation he was forced to endure is highlighted by the implicit binary opposition where reference is made to the teacher’s pets, thereby placing these children in a favoured and privileged position, which serves to emphasise the disenfranchised position Stefan found himself in. Specifically, Stefan draws on the egalitarian discourse as an ideal and opposes it to the privilege discourse as origin of unfair class divisions, when he states: “a fellow pupil as old as me now has to teach me …”. Effectively, Stefan is able to legitimise his claim that utter injustices were committed against him throughout his life and in various contexts. Another example of the injustice discourse is prevalent when Stefan explains his dislike of the snobbish academic type:

Yes, that’s how I feel, yes, they look down upon you, you are rated if you can’t spell and write properly, because you’re not an educated human being.

Apart from being the cause of severe interpersonal injustices that he has had to endure along his way to success, Stefan also describes the personal struggles he faces as a consequence of his dyslexia:
I think my mental handicap of ... I always feel I ... like I said to you earlier, since my schooldays it broke me down so that I am not that full go-getter which I maybe could have been. It shattered it for me since school. That is maybe the only negative effect that it left in my life, that I always felt unworthy in comparison to many other people, even still now sometimes. I’m learning it more now in my life, a lot more due to the type of work that I do, where you have to have a much thicker skin. I’m a very sensitive person, and now I’m learning to have a much thicker skin just to help ...

Stefan continues on this train of thought later on in the discussion:

... my dyslexia is my hindrance, it has never been a bridge to me, and it’s a hindrance for me where I am now, because now I have to write even more reports and paperwork and read contracts. It actually still becomes more of a hindrance to me. I overcome it by using my common sense as much as possible.

It is clear from the two excerpts above that Stefan utilises a form of counterfactual thinking in order to imagine the possibilities that could have been open to him were it not for the devastating effects of dyslexia. Effectively dyslexia is objectified as an obstructive agent that impedes the purposeful action that would allow Stefan to reach his actual potential. If one applies the elements of purposeful action to the above
statements, then performing at one’s actual potential would constitute the purpose, whereas reaching that actual potential would constitute purposeful action. In other words, people without dyslexia reach or strive (purposeful action) to (purpose link) perform at their full potential (purpose). However, in Stefan’s case, purposeful action would constitute reaching or striving plus overcoming the obstacles of dyslexia in order to perform at his full potential.

One can see then that, with the odds stacked against him, he would be able to take more credit for his achievements as he has to put in so much more effort to attain them. In the ending statements of each excerpt above, Stefan gives instances of how he has managed to overcome the obstacles posed by dyslexia. In each case the statements are framed in the active voice with Stefan occupying the subject position who is busy achieving something. Also, the verbs utilised in these statements suggest pro-active behaviour on his part. Thus, in effect, the reality is created where he occupies an active role in overcoming the oppressive effects of dyslexia, and therefore all success is attributed to his own efforts. Consider the differences in meaning, would these statements have been framed differently. For instance, consider the differences in meaning should one substitute the frame “I am learning …” for the frame “I am being taught …”.

By highlighting the injustice discourse Stefan is able to legitimise his feelings of resentment towards those types of people that he categorises as academic snobs. Of
course in contexts where power imbalances are definite and clear, a revolution is only possible when the playing field is levelled.

It would seem that by drawing on the obstacle discourse Stefan is able to construct a reality where his personal achievements are weighed against the struggles he has had to face. The emerging image of the immensity of the impediments set by dyslexia serves to inflate the gravity of his personal achievements for which he can take sole credit. In as far as his perseverance and hard work reflect his ability to transcend hardships and make a success of his life, Stefan is able to claim the praise of society for upholding the societal values of hard work and success.

Stopping short of bowing to the praise of society, however, Stefan also airs his disapproval and resentment of the status quo as upheld by those types of people he refers to as academic snobs. Stefan’s rebellion against the status quo finds its legitimation through his references to the injustice discourse. As he states, despite his achievements the tendency is still for his nemeses to elevate their own importance:

*I have a BTech, not a BSc behind my name, and in this old country of extreme academic snobbism, the guys make sure that a wall is built to separate a technologist and an engineer ... there's a lot more engineers than technologists in the country, so they have a strong front of “but you’re not really equal to us”.*
It seems then that to achieve liberation in this context where the power imbalance is so definite and clear, the only option is to level the playing field.

**Wicked institutions and the foot soldiers of the status quo**

Another assumption that is widely held in Western cultures is that of attributing intent to evil and in doing so, evil is personified as a twisted humanlike figure or as conniving and oppressive institutions. In the previous section, it was found that Stefan utilises the injustice discourse to express his fight against oppression and prejudice as a result of his dyslexia. Given the complementary nature of relationships, an agent of oppression needs to be constructed or identified in order to execute the oppression in question. In this sense then, dyslexia provides the basis for the agents of oppression and prejudice to achieve its purpose.

While individuals often take on or are given the role of the villain, they are more likely to represent the foot soldiers of a larger evil, which often manifest in the guise of seemingly helpful, but inherently wicked institutions. Considering the following account, and others like it, the impression is created that Stefan’s chief nemesis manifests in the form of academic idealism:

> She [Stefan’s mother] had this English book and the extra English classes that she tried to give me and, uhm, I can see these books in front of me, I still get an allergic reaction when I see those books in front of me, and
uhm, my mother tried to teach and drill me and gave reading exercises.
And, uhm, I had been a bit drilled, so there I already developed a total
anti in any remedial remedy.

Further on in our discussion, Stefan expands the concept of wicked institutions to include
individuals as well:

And I remember my one teacher in Standard 9, it is a type of academic
person, they are highly academically intellectual, he can do paperwork
with ease, he is good with languages, he is good with writing. If I see a
person like that I get highly upset. Uhm, I won’t share with that person
that I have dyslexia, because they just don’t have any comprehension and
understanding for it, and you often find these guys in business ... but with
the guy on the floor, the artisan on the floor that I see often, oh, we can
have a good time teasing each other ... and it’s ok.

In the first account above, Stefan draws on a personal and specific experience where he
was forcefully subjected to the academic ideals of his mother. Here the clear message is
that his mother’s intentions were to help him overcome his reading difficulties, but the
method of her ways is blamed for his aversion to academic idealism. This is explicitly
communicated in the final statement of his first account, where he attributes his “anti” to
remedial remedies to being drilled. Once again the action of being “drilled” evokes
images of forced compliance and hence relates to the idea of oppression, yet remedial
remedy is offered as the official name for this type of academic idealism, thereby disguising it as a ‘healing’ practice. Although her intentions might have been good, Stefan’s mother is presented here as a foot soldier, or applicant of the greater evil of academic idealism, as she bought into and imposed on him one of its guises, namely remedial learning.

The second excerpt above goes beyond the institutional level and academic idealism is presented as a characteristic that certain individuals possess and that accounts for their oppressive and prejudiced attitudes to people, like Stefan, who do not conform to their ideals. Stefan attributes his refusal to disclose his dyslexia to these individuals’ inherent lack of understanding of the condition. The implicit message is here that their knowledge of his condition would provide them with the basis of acting out their oppressive and prejudiced natures.

There is also a binary opposition at work in the second excerpt where the academic snobbism is contrasted to the more humble artisans on the floor. Stefan’s explicit alliance with the artisans then affords him the quality of humility by association and their teasing of each other is legitimised by the operation of the commonality discourse. In other words, they gain the right to tease each other about their academic deficits due to the fact that they share this aspect. In fact, Stefan describes his doubts that the academic idealists described above would ever have an understanding for his condition:
I don’t think they have the comprehesion to understand that people can suffer from this. It comes so naturally for them, it’s so easy for them to write, that they can’t think ...

From this statement the idea clearly emerges that academic idealists will not have the ability to comprehend his predicament, due to the fact that they will never have the experience of struggling to write, because they are naturals at writing. In other words they will not believe it, because they cannot see or experience it. In the following excerpt it becomes clear how Stefan utilises the discourse of ‘you’ve got to see it to believe It’:

The irony with these people that I have also recognised is that, in the business world they end up as just paper pushers and managers, but they are not entrepreneurs. They don’t really make the business world go around, they just execute very thoroughly, very clinically, projects or business and, uhm, planning and goals ... but they aren’t your entrepreneurs who can do a thing differently and think differently and the like. They are clinical executioners.

Again the academic snobs that are referred to above are presented as very capable and efficient individuals owing to their natural talent. However, Stefan points out how this natural talent of theirs is actually an impediment to creativity and entrepreneurship by virtue of their idealism. Although Stefan does not make explicit mention of himself in the above excerpt, one should take note that the discursive context that prevails at this stage
of the discussion is one where Stefan is asked to define himself in relation to how other people react towards the knowledge of his dyslexia. Stefan then created the opposition between himself as a person with dyslexia and the type of academic snob he refers to above, which is evident in the following statement:

... I’m going to categorise the person. There is a certain person and it comes from grade ... from that Standard 1 class with me. That bliksem [a derogatory term for an irritating person] who sat there in that corner in that class [points to opposite end from where he sat], who is good with language, he’s just got the knack for it...

Thus by pointing out the lack of creativity of the “clinical executioners”, as he calls them, Stefan implicitly defines himself as possessing the creativity and entrepreneurship that are so valued in his occupation. One can therefore argue that Stefan’s abilities to cope with the debilitating effects and social stigma of dyslexia are translated into qualities of creativity that he can take ownership of. With the scales tipping in his favour, Stefan is able to bring about a personal revolution in the construction of his identity, a liberation that takes on new meaning in light of his family background.

Daring to be different

As is true for every one of us, heroes, including revolutionaries do not rise out of social and familial vacuums. It is known throughout history that the remarkable achievements
of revolutionaries such as Nelson Mandela and Ché Guevara are intimately shaped by the social, familial and political contexts that helped define them as individuals. Stefan’s story is no exception to this observation and he provides numerous accounts of how these contexts shaped his perception of self as a person with dyslexia.

Having been born into a well-educated family with significant social status, it seems almost ironic that Stefan’s story is constructed with a strong revolutionary narrative thread. When one takes a closer look though, one can notice a coherence that binds Stefan’s struggle for personal liberation closely to his experiences within his family of origin. Stefan’s account of growing up in a highly professional household sheds more light on this:

... Both my parents were professional people and I am the last one, and I say it straight and I told them, they didn’t raise me, I raised myself, school everything. And uhm, I never really had a close relationship with my parents. Still now not even with my mother ...

Stefan’s description of his parents as professional people draws strongly on the oppositional images of family and work where it is often advocated in society that the two are mutually exclusive in terms of priority placement. In other words, being labelled a professional person the assumption often follows that this person places a higher priority on his or her career than on family, and the opposite applies to a family man or woman. Thus, Stefan’s word choice, “professional people”, emphasises and also to an
extent discursively legitimises his claim that he was afforded little of their time. Being the lastborn child further strengthens the idea that his parents ran out of time and patience in raising him and therefore he had to tend to his own upbringing. Having lived through these conditions, it is little wonder that Stefan would rebel against his family’s professional culture and values.

When asked about the reason why he places such a high premium on family, Stefan offers the following response:

Yes and no. I see my mother’s faults and I am a lot of my mother, and my mother, look I am an academic person, a thinker, and my mother decided that her career is more important to her than her children. And I saw it, I saw the consequences of it, then I decided the opposite.

When considering these statements, it is evident that Stefan’s relationships with his parents had a big impact on his aversion to academic idealism. By using the working man or woman discourse Stefan highlights the devastating effects it had when his parents chose work over him. Here the notion of professional idealism, which is closely linked to academic idealism, is placed in the floodlights once more.

Notice that Stefan’s mother is presented as having made a conscious and deliberate choice to place her career first. By pointing out his similarities with his mother, Stefan presents himself with the same family-work dilemma that his mother faced. Due to the
fact that Stefan describes himself as an academic and thinker, just like his mother, his choice to place his family first gains much more gravity since it entails a sacrifice that his mother was never willing to make. In effect, Stefan is able to highlight his own decisive power, despite his professional ambitions, and he presents himself as having the ability to resist the temptations of professional idealism.

The differences between Stefan and his family seem to have played an important role in his current construction of his identity. Stefan mentions the difficulties he had to endure as a result of his family’s lack of acceptance of something he claims to have no control over:

*Where I came from an academic family, and a dad who was fantastic at spelling and brothers and sisters who were fantastic in English and writing essays, and I couldn’t do it. So it was obvious to everyone, and thus not acceptable.*

Here the differences between Stefan and his family take on special significance. Having defined his family as an academic and professional family, Stefan proceeds to point out his inability to perform well in English and writing essays. Importantly, in this account he attributes his difficulties with language to his lack of abilities, whereby they become something he has no control over and cannot change. He then describes the other members of his family as possessing exceptional language abilities, which create a polarity that divides him from them.
The *salience discourse* then serves to underline the alienation he had to endure for something he could not change. It must be said again that the agent of oppression is not so much his family members, but rather the academic idealism they subscribe to, as it was this idealism that served to underscore his difference from them and robbed him of a caring family.

**Revolution personified**

Considering Stefan’s background and the difficulties he faced while growing up, it would be hard not to be impressed by what he has achieved in life. A great deal of his conversation on his experience of growing up with dyslexia is focussed on the various personal and interpersonal difficulties he encountered, some of which he attributes to dyslexia itself, while mostly his difficulties are indirectly related to it, such as people’s lack of understanding of Dyslexia. For instance, he mentions the following:

*Uhm, so the word dyslexia did not bother me. To hell with people. I mean you also learn to develop a thick skin against things like that, but the label of I cannot read, and I cannot spell, that bothered me at school, because that was obvious to everyone.*

In this statement Stefan explicitly defines his biggest difficulty not to be the label of dyslexia, but rather the symptoms or behavioural components that underlie the label. In other words, he draws a distinction between the label dyslexia and the reading and
spelling abilities that it refers to. As long as the difficulties with reading and writing are attributed to dyslexia, they are externalised, and Stefan is able to shrug it off. However, when people attribute his difficulties to a lack of abilities on his part, then Stefan was bothered by it. Furthermore, seeing that people at his school did not grasp what dyslexia was, any reading and writing difficulties were likely to be attributed to his lack of ability rather than to dyslexia.

However, in contrast to his hardships, Stefan also relates numerous ways in which he has overcome these ‘dyslexia difficulties’ by drawing on his inherent personal qualities:

1) **Researcher:** [Would you say that] ... you developed certain qualities, which otherwise ...

2) **Stefan:** ... I would rather say that I’ve found ways to cope and deal with it ... I think the qualities that I have as a person, I would have had the same qualities whether I had dyslexia or not. I am a technical person by nature, I have very strong values in the business world with the manner to handle a client and function. I can decide very strong, be decisive, I can take very strong ownership of a problem and sort it out or take responsibility for the results that go wrong. And these are characteristics of me as person. Now if I could spell or not, those characteristics could not change.
My question in Turn 1 is a request for Stefan to consider his personal qualities in terms of how they might have been influenced by his learning experiences, especially experiences related to dyslexia. Stefan denies owing any of his personal qualities to dyslexia and attributes all his admirable achievements to his innate qualities. Stefan subtly underplays any contribution of nurture, or lived experience and learning, to his commendable personal qualities. By defining dyslexia in its simplest form in the above, i.e. as an inability to spell, and posing the possibility of it having played a role in determining his personal qualities, becomes a ridiculous question. This is because the relational aspect of the way in which his contexts were shaped by his having the label dyslexia is removed from the equation, leaving no room for the nurture side of the opposition.

Therefore, the nature versus nurture contingency plays a significant role in his construction of his identity. Remember that Stefan defines his dyslexia solely as a hindrance and therefore, by attributing all his achievements to innate qualities, he is able to take sole ownership for it. Also, as stated earlier, dyslexia as a hindrance serves to inflate the gravity of his personal achievements by virtue of its opposition to it. Therefore, the nature versus nurture discourse aids Stefan to highlight his achievements in spite of the oppressive forces related to his dyslexia. Accordingly Stefan can claim his liberation from the seeds of doubt in his own worthiness that was planted through academic idealism and its foot soldiers.
Leaving a legacy for generations to come

The image of society as consisting of organised systems of individuals as well as larger than life ideals and values implies a delicate balance and synchronicity of its components in order to maintain proper balance and hence organicity. It would thus follow that every act of conformity or defiance impacts on this balance, but very few disrupt it to an extent that they bring about a new order in society. Individual revolutionaries may be the faces of change, but whether their efforts are significant in history depends on the generations that follow.

Similarly, Stefan’s personal liberation might be framed as a personal revolution, but it does not mean that he has changed society or even impacted on academic idealism as a wicked institution. His victory is rather a moral one, but it is a victory nonetheless, for it has implications for how he relates to those individuals in his immediate surroundings. More importantly, his struggle for liberation from the stigma of dyslexia holds implications for how he relates to his children, the generation to follow:

*I can’t really say that it impacted on my relationships, but of course, I keep an eye on them to see what their abilities are ... something that I can say it influenced, look library time is an important time in the week and I make sure it happens, and I made sure that I get my children to read, because that’s something my parents did not do with me, and it might have helped to dyslexia.*
After providing an account of his daughter’s zest for reading, Stefan continues with his thoughts:

That is something I am very proud of, you know, but I taught them, I got them to read. Uhm, with my laaitie [an Afrikaans colloquial term of endearment, referring to a male child], we are naturally very sensitive with education, and maybe the fact that I have dyslexia I’m very, very understanding and patient to teach him to speak, you know, we are now on the talking phase ... so I put in a disturbing amount of effort on interactive talking with him ...

From his accounts above, it is evident how Stefan draws on the nurture discourse to make salient the intergenerational revolution that has occurred. Specifically he utilises his parents’ lack of purposeful action to encourage him to read in order to posit a causal link to his developing dyslexia. An interesting contrast to take note of is the different contexts in which the nature versus nurture discourses are applied in Stefan’s story. Remember that Stefan utilised the nature discourse to take ownership of his own achievements, and the challenges he was confronted with as a result of dyslexia served to inflate these achievements. Here Stefan draws on the nurture discourse to illustrate how his dyslexia might have come about.

The differential use of the nature versus nurture discourses then finds importance in the purpose it serves for Stefan’s construction of self as an individual possessing personal
agency to control his environment. If he, for instance, were to utilise the nature discourse to account for his dyslexia, it would imply that dyslexia is an innate quality of Stefan’s being and the humiliation he endured could not be helped. Such a construction would leave little room for personal agency in order to make an impact on his children’s futures. However, the nurture discourse suggests that something can be done to prevent or limit the impact of dyslexia and other conditions, such as Down’s syndrome.

**Conclusion**

In his story of liberation it is evident how Stefan combines and contrasts various societal discourses in relation to his dyslexia and its stigma to construct his identity as a person living with dyslexia. The nature versus nurture discourses are good examples of these discursive interactions that allow Stefan to construct himself as an empowered individual in that he can avoid the mistakes his parents made with him by taking more interest in his children’s performances. In fact, as he affected this intergenerational revolution, Stefan has more to be proud of than simply his personal liberation from the stigma of dyslexia, for his appreciation of the remarkable struggle he endured inspires him to do things differently with his children and thereby leave a legacy in their lives. In this sense, it might be true that heroes are born by a wish to change the world, but it is through remembrance of their brave attempts that heroes are immortalised.
With the conclusion of Stefan’s story, the focus will now shift to the third and final participant in this study. Mariëtjie’s experiences of adapting to her anxiety attacks and the revelation that she has an anxiety disorder are discussed in more details below.

**Anxiety Disorder: An heir to the throne**

Mariëtjie, an Afrikaans-speaking, white woman, is a dedicated wife and mother of two boys, and is currently assisting her eldest son’s girlfriend with her pregnancy. She is currently 35 years old and confesses that she is very excited about the birth of her first grandchild, although the stress that comes with the pregnancy causes her to become very anxious at times. On 1 January 2009, after celebrating the New Year with her colleagues from the supermarket where she worked, Mariëtjie had a severe episode of extreme anxiety at work. Later her doctor would diagnose her with an anxiety disorder, i.e. what she calls “anxiety attacks”.

Mariëtjie’s childhood was characterised by her assuming much responsibility at home, and she made the decision to leave school at the age of 15 years to help out at home. Although she thinks of herself as a housewife, Mariëtjie admits that she enjoyed working at the deli in the supermarket, and she regrets that she had to give up her job after being diagnosed with an anxiety disorder. Although her journey of adjusting to living with an anxiety disorder has been fairly brief, her dedication, hope and faith for a fulfilling future have brought her a long way in going forward.

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4 Real name is used on participant’s request.
The day the crown dropped to the floor

When one considers the words of Romeo’s tormented lover Juliet, “a rose by any other name would smell as sweet”, one can infer the message that names are arbitrary strings of letters that only obtain their meanings through their association with the objects they refer to. Therefore, if one were to change your name from Jack to John, one could reason that you would still remain the same person and your new name would have the same meaning to those around you, as the old one had.

If one considers, however, that all names are given to people by certain other people who have certain reasons for their choice of names, then it becomes clear that the meanings of names are not arbitrary and do not reside in the object or person who it refers to. For instance, whether your mother chose your name merely because it had a nice ring to it, she still had a reason for christening you with it and thus your name carries a certain history and consequently has certain meanings to those around you.

The reason I share the above argument is because I see a definite relevance in it with regard to Marietjie’s feelings of panic and confusion after her first intense encounter with anxiety. In the following excerpt, Marietjie draws on the naming discourse, which suggests that the name of the problem contains the solution to it:
1) Researcher: ... so you say that you had this [anxiety] attack, but you didn’t know what it was, did you perhaps have any ideas in your mind about what could be wrong?

2) Marietjie: No, no, no, I was very nervous, because I didn’t know what was wrong with me. And the anxiety scared me, because now you don’t know what is wrong with you.

Further in the discussion she elaborates on the importance of her search for the correct diagnosis:

3) Marietjie: ... I started crying later on. I told my husband that I can’t carry on like this, because I don’t know what’s going on with me, and the doctor keeps saying I have the flu. He then said “I’m accompanying you to the doctor now, until he’s sorted out everything, you can stay there with him”, because later on I started to feel like I’d commit suicide, because I don’t know what’s wrong with me. And the anxiety only got worse and worse, because I’m not being diagnosed properly.

What is clear in the content of Marietjie’s accounts above is the sheer degree of discomfort she experienced as a result of not having an official name to give to her troublesome experiences. In Turn 1 above, my question is posed as a request for Marietjie to reflect on the meanings she attributed to her experiences in the absence of having an
official name for them. Again, as with all reflective accounts of experiences, the meanings are not recalled from the past, but they are created in the present process of reflection and presented as if they existed back then. Therefore, my inherent request is for Marietjie to engage in the act of constructing these meanings of the events in the past.

In Turn 2 Marietjie declines answering the explicit question of what her personal theories were regarding what could be wrong, but responds to the implicit request by reflecting on her lack of understanding what was wrong. Here it becomes imperative to notice the attribution of purpose as a means to legitimise her experiences.

By using the three elements of purposeful action, her statement can be presented as follows: I was very nervous [purpose] + because [purpose link] + I didn’t know what was wrong with me [purposeful action/state]. Thus her anxiety is posed as a consequence of her insufficient explanatory modes, and can also be presented as follows: I didn’t know what was wrong with me, therefore I became very anxious. This statement then presents Marietjie with a course of action in getting a grip on what she was experiencing, that is to name it and explain it.

The importance of finding the official name for her problem is highlighted in Turn 3, where she juxtaposes the necessity of naming her problem with the drastic option of suicide, thereby creating a dilemma. Accordingly, the necessity of discovering the correct name for her problem is elevated to a matter of life or death.
In the last statement in Turn 3, Mariëtjie again attributes her worsening anxiety to her state of not being able to explain it, but this time the purposeful action (or lack thereof) resides in an agent separate from herself, namely the doctor. As doctors perform the function of diagnosticians in society, their failure to provide an official and satisfactory name for her problem highlights the link between not knowing and her intensifying anxiety, thereby further legitimising the need to name her problem.

By drawing on the naming discourse, Mariëtjie emphasises the lack of agency she experienced as a result of not being able to explain or give meaning to her experiences of anxiety. Although she reports being devastated to find out that her official diagnosis is an anxiety disorder, Mariëtjie does report that this knowledge provides some relief and feelings of control: “Now I can handle it a bit better, because I know it’s my anxiety attacks, and I keep saying to myself when it happens: ‘I’m going to be alright’”. Having officialised her condition as anxiety disorder, she can now proceed to ‘discover’ its underlying meanings and work towards making changes in her life. Her conviction of the necessity to be diagnosed properly leads to a different but related discourse, also prominent in her story.

**To catch a crown**

Mariëtjie’s insistence on establishing the real name for her experiences of anxiety seems to operate on the logic that by finding its name – its real name – the diagnosis as a sign might point to something beneath the surface, something that might have caused the
problem to come into being. The hope would then be that knowing the nature and cause of the problem might suggest possible ways or areas to attend to in order to arrive at a solution to her problem. As she describes:

1) Researcher: ... if I would have to ask you now, what is your diagnosis, what would you tell me? Like what is your disorder?

2) Marietjie: I would say to you now that I get anxiety attacks, yes. I get anxious when I start to stress, or anxious when I start to get worried, or uhm, how can I say, if a person, if something looks like it can be dangerous or something, then I get anxious, yes. But most of the time it is like Amands [her psychologist] said, I get anxious if I, uhm, feel that I must help people and like when I see people are in danger or something.

The emerging definition of our interactive context, as framed in my question, is an informative one. Consequently, my question to Marietjie is seemingly purely based on seeking a factual answer, i.e. that she is diagnosed with anxiety disorder. However, as seen from Marietjie’s response in Turn 2, she personalises her answer by saying “I would say …” thereby drawing on her own understanding of what her problem is, and she redefines the interactive activity as one of informing through personal reflection. This suggests that her definition of her problem reflects the personal meanings that she has attached to it, and therefore draws on the name as a sign discourse.
In her first statement in Turn 2, Marietjie defines her problem in terms of the official diagnosis of “anxiety attacks” and it becomes an entity in itself. The problem is thereby objectified and she distances herself from it. Therefore, anxiety attacks become an external infliction that invades her day-to-day life, something over which she has no power other than to defend herself from it. In the remainder of her statements in Turn 2, Marietjie proceeds to offer the meanings behind her anxiety attacks and eventually ends up with a relational definition of the problem.

There is a gradual progression in her definition of the problem she is faced with as she reflects on the underlying meanings thereof. For instance, in her second statement in Turn 2, Marietjie defines her problem as an emotional state that resides in herself, but it is something that is brought about by her other mood states, like being worried. This intrapersonal framing of her problem allows for some degree of personal agency, but this agency relies on her annihilation or avoidance of other natural mood states. Therefore, if she can avoid being worried, she can control her anxiety.

The difficulty that is clearly evident in Marietjie’s attempts to define the meanings behind her problem suggests a search for a satisfactory explanation in terms of purposeful action. Her statement “uhm, how can I say …” suggests that she was unsatisfied with the explanation provided before, and will continue to express a more satisfactory definition. Marietjie then starts with a relational definition, “if a person …”, but then negates it immediately after by correcting her statement (I added the negating word for illustrative purposes): “if a person, [no] if something …”.

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In finally arriving at a relational definition of her problem, Marietjie utilises a form of legitimisation known as *authorisation*. She is able to legitimise a relational definition, which seems to be most satisfying to Marietjie in terms of its meanings, by referencing an expert on the field. Here her psychologist is credited for the relational definition that adds legitimacy to her interpretation by virtue of the expert discourse. Her final statement in Turn 2 above, “I get anxious if I … feel that I must help people …” no longer situates the problem in Marietjie herself. Rather the problem is situated in the way she relates to others. Therefore, the framing of the statement (via the word *must*) indicates that her helping actions are motivated by duty to others, and also that others contribute to the problem by making her feel she has a duty towards helping them. This relational frame then provides more possibilities for personal agency on Marietjie’s part, as the meanings she ‘discovered’ that explain why she is anxious point to a need to alter her interpersonal roles.

**Sharing the weight of a crown**

If one accepts that all names acquire meanings as a result of the interpersonal nature of naming processes, the resulting historicity that accompanies names mean that people inherit certain expectations to live up to as a function of their names. This is most clearly illustrated in the inheritance of family names. For instance, when a mother decides that her son should be named after his father, her decision is made in a certain context which affords it certain historical significance.
For example, take a couple that has had difficulties conceiving and finally gave birth to their first child ten years after their first attempt to extend their family. This child is then their first child and potentially the only child they might conceive, and happens to be a boy. Given these contextual factors, the decision of naming this child after his father likely carries with it the significant, yet implicit expectations that he would represent his father as well as his hopes and dreams for carrying the family values into the future. In such a case, his name would be imbued with certain responsibilities and expectations that symbolise how his parents might relate to him, even from before his birth.

Being part of a family herself, Marietjie also occupies certain roles that are governed by the names she carries and the symbolic meanings they have for those intimately connected to her. Marietjie is not only Marietjie, but she is also mother, wife, daughter and friend to those people who care for her. Furthermore, the roles that she occupies do not remain static over time, but evolve with the addition of new labels carrying new symbolic meanings.

It can be argued that the symbolic nature of names holds true for most labels that people appropriate over time and informs much of how our roles are defined within our family systems (Andolfi, 1983). After having appropriated the anxiety disorder label, Marietjie describes the impact it had on her role as a member of her nuclear family network:

1) Marietjie: ... Ok, my husband supports me a lot and it helped a lot.

   He’s terribly supportive, my children as well ...
2) Researcher: How does your family support you in terms of [the anxiety disorder]?

3) Marietjie: Yes they support me a lot. For them it’s also still a new thing. If my youngest son, if he, he says “Mom, don’t you want to lie down for a bit, or, or go and rest a bit?” And he’s very worried and uhm, luckily when I get the anxiety attacks then I try to keep it away from him, because I don’t want him to see it …

My question to Marietjie in Turn 2 is an invitation to elaborate on the support she mentioned receiving in Turn 1 above. Essentially, I am asking her to provide examples of what she perceives support to be. The emerging definition of our communicative activity becomes one of outlining the perceived changes in her roles in the family.

In Turn 2 Marietjie reconfirms the amount of support she receives as she mentioned in Turn 1, after which she provides legitimation for her family’s reaction, in that they are still adapting to the new situation. This might indicate that the support her family thinks they provide is not exactly the type of support she actually needs. This interpretation is confirmed by her account of her son’s worried reaction towards her anxiety. After giving this account, Marietjie offers the statement “… when I get the anxiety attacks then I try to keep it away from him …”. This statement suggests that her family’s worries about her, which she previously defined as support, actually become another stoke in her fire to which she must attend.
To appreciate her statement, one should keep in mind the prescriptive roles that preside in family contexts. Being a mother, Marietjie’s prescribed role is to protect her children from the worries of the world. It would then seem natural that Marietjie experiences disease in the sudden reversal of roles, where her son now becomes worried about her. Marietjie confirms this interpretation later on in our discussion when she says:

\begin{quote}
I am scared that they would be worried about me all the time, and that they rather, like the youngest one, that they rather concentrate on their schoolwork and be with his friends. I don’t want him to see a depressed mother. He must feel happy, and not feel that he can’t go here or there now, because his mother is not feeling well...
\end{quote}

As mentioned in the introduction to this section, Marietjie describes herself as having been a dutiful person from early on in her life. Being duty-bound, she has had to make many sacrifices in her life in order to assume the responsibilities of taking care of others. As mentioned earlier, the official underlying meaning of her anxiety disorder that she bought into is that her anxiety is caused by a feeling of duty towards others. This then implies that Marietjie’s sense of duty has become extreme and detrimental to her wellbeing. When she appropriated the anxiety disorder label, the notion of family support became yet another duty that she was benevolently expected to accept, as she explains:

\begin{enumerate}
  \item Researcher: ...what were your family’s more immediate reactions [after her being diagnosed]?
\end{enumerate}
2) Marietjie: My husband immediately said “You’re not going back to work, there is too much stress at work”. I should get more relaxed at home.

3) Researcher: Was that what you hoped for? Was it the manner you hoped he would react?

4) Marietjie: No.

5) Researcher: How would you have liked it ...?

6) Marietjie: Uhm, I would have liked them to say “Ok, it will come right, go back to work”. But he said “You’re not going back to work, there’s not a chance. You can stay at home, relax more”.

Marietjie’s admission of her disappointment in her husband’s reaction indicates the dissonance that she experiences with regard to the support she receives from her family. Notice that her definition of what she perceived support to be in Turn 6 is at direct odds with her husband’s decision of what he presumed to be in the best interest of her wellbeing. The benevolent intent of his decision would make it hard for Marietjie to oppose his decision, especially given the context in which his decision is made. Because of the symbolic meaning of the anxiety label, Marietjie’s family members are alerted to the fact that she needs to be protected from stress. Thus, the empathy discourse serves to legitimise her husband’s decision that her continuing work would harm her further.

Having bought into the anxiety label herself, especially given its explanations regarding the causes of her anxiety attacks, Marietjie finds it difficult to oppose her husband’s
decision. In response to my question regarding what the communicative value of her husband’s choice was to her, Marietjie has the following to say:

1) *Researcher: The fact that he told you that you shouldn’t go back to work, what does it say to you about yourself?*

2) *Marietjie: That I, that my body isn’t as, can’t go on as I’ve done in the past, yes.*

By asking her to reflect on the communicative value of her husband’s decision in Turn 1, I invite Marietjie to interpret her husband’s decision in terms of what it implies about her perception of self. Marietjie’s statement in Turn 2 again draws on the name as a sign discourse. Although it is her husband’s decision that is interpreted as a sign that she should change her lifestyle, her interpretation still draws on her diagnosis as the basis for her husband’s decision. Therefore, while Marietjie’s appropriation of the anxiety label holds certain meanings for her family members, her interpretations of how they react towards her seem to have certain implications for how she defines her identity. In this regard, her family’s reactions reinforce the reality suggested by the name as a sign discourse, i.e. that she needs to alter her lifestyle and become less dutiful. In this sense Marietjie’s duties in her family are redefined and it can be said that her new duty towards her family is to be less dutiful.
Advisors to the throne

It is often the case that people find that despite their best efforts to prevent it, they turn out to be very similar to their parents. Similarly, there also seems to be a great tendency for people to suffer the same difficulties and develop the same ailments as their parents, which in systemic terms are referred to as intergenerational patterns or redundancies (Becvar & Becvar, 2000). Such intergenerational patterns make it hard to dismiss the possibility that people can achieve different outcomes despite being afflicted with the same difficulties as their parents. In other words, it sometimes feels as if the apple does not fall far from the tree, but rather on top of it.

Having had personal experience with her mother’s anxiety attacks, Marietjie describes her fears when she found out that the same fate has befallen her:

... the thing is, my mother is already so far along with her pills that she can’t go off it. And it doesn’t make her a good, a good person. On the contrary, it makes her an ugly person. Sometimes she gets mood swings ... The one day she is good, another day she will swear at you out of the blue, and stuff like that. I don’t want to become like that, yes. That was my biggest fear.

In this account Marietjie draws on her personal experience of her mother’s difficulties with anxiety to draw parallels to her own possibilities. It could be said that her mother’s
behaviours represent a possible blueprint for what her life can become, given the similarity of the condition they share. Marijtjie’s explicit use of the good/bad binary opposition emphasises her disapproval of her mother’s behaviour, yet this behaviour is attributed to the medication and not as a characteristic of her mother. Lastly, her mother is presented as lacking decisive power in coping without her medication, which creates a pretty grim and rigid image of what it means to have an anxiety disorder. In the final two statements in the preceding excerpt, Marijtjie distances herself from the image created, effectively communicating that she does not buy into this rigid image. Notice that the statement “I don’t want to become like that” is framed in the future tense, thereby indicating a wish or intention, whereas the statement “That was my biggest fear” indicates that her fear has already been extinguished.

In renouncing the rigid image her mother has sculpted for her regarding what to expect in her future, Marijtjie enlists the hopeful image that she is able to construct with the support of her other advisor, her sister-in-law:

1) Marijtjie: The one wants to tell you you’re going spend the rest of my life, my mother, she says to me I’m going to spend the rest of my life living with pills and stuff, which I don’t want to do, and my sister-in-law says it will get better sooner or later, that I can live without the pills, yes.

2) Researcher: ... who do you believe?
3) **Marietjie:** My sister-in-law. The reason is, she also worked as a nurse for years, and now only went on pension. So I trust her, her mother also had anxiety attacks, so.

In Turn 1 above, Marietjie defines the possibilities of her future outcomes in terms of the contingent images as posed by her mother and sister-in-law, both of whom have personal experience with anxiety disorder. After Marietjie presents her mother’s image, she explicitly renounces her agreement with it in terms of her own wish. The framing of her renouncing statement, “I don’t want to …” presents her as an agent with decisive power to choose the course of her future. Her sister-in-law’s testament to her hope for a better life is then presented. Notice that the framing “I can live without the pills …” reiterates the possibility for decisive power. The effect created by the framings of these hopeful images is one of empowerment, where Marietjie is presented as having options to determine her own outcomes.

In Turn 3 Marietjie explicitly announces her allegiance with her sister-in-law’s predictions, and proceeds to legitimise her belief through appealing to her sister-in-law’s personal as well as professional experience with anxiety attacks that spans over years. Marietjie’s construction of herself as an individual with choices and power to determine her own outcomes is therefore strengthened by the authority that her sister-in-law’s experience affords her predictions.
Making the time to fly

There seems to come a time in every person’s life, where the task to individuate from the family mass is an important and imperative function of your own benefit. Having spent most of her life sacrificing her own needs in the name of duty to her family, Marietjie has now come to a place where she is kinder to herself. As she describes:

*I am more relaxed, I’m more relaxed now yes ... If, on the day, I really don’t feel like cleaning, then I just sweep the floor and clean so that it looks clean, and then I take it easy, take the rest of the day off. Uhm, before the anxiety attacks, the house had to be spring-cleaned every day, must be clean. Everything must be perfect. Now I’m not as fussy about it, if there is a bit of dust on the television, then I’ll leave it ...*

Marietjie’s current description of herself is in stark contrast to the one before her anxiety disorder diagnosis. Particularly, she now presents herself as having power to make choices whether to clean or not. Her day-to-day activities prior to her diagnosis are described as having been governed by a compulsive drive, something that she had to do and had no control over. Marietjie’s construction of self has developed into one of a person who possesses the agency to make her own decisions and accept responsibility for her choices.
The anxiety disorder diagnosis then, as disruptive and devastating as it is, has made an important input into Marietjie’s family system. Through its symbolic meanings that impact on how Marietjie and her family members think and act, being diagnosed with anxiety disorder served to disrupt the family balance that kept Marietjie in her dutiful role:

... Before I had to do things. When it was someone’s birthday, then I had to bake a cake and make party stuff. Nowadays when it’s someone’s birthday or something and I don’t feel in the mood, then I’ll say “No, I don’t have the energy for it”.

She also describes the positive changes that she made as a result of her shifting roles. Particularly, she seems to relish the freedom she enjoys now and the appreciation that she has for every moment of life. Marietjie describes this feeling in response to my question of whether she notices any positive differences in herself as a result of her diagnosis and the experiences that followed:

No not really. Just the fact that I now take every day, I always, oh planned things a week before the time, nowadays I take it one day at a time ... I try to live every day that I have to the fullest of my ability. Like if my child says “Mom, let’s go to the mall”, then I always said “Oh, let’s go tomorrow or the day after”. Now I say “Ok, let’s go”, because I have
now, maybe tomorrow won’t exist anymore, yes ... I try to live every day
in the full, that’s all that changed me, my view on life.

It is evident then that through her experiences and struggles with adjusting to her diagnosis, Marietjie managed to construct the meanings that resulted in the choice of changing her lifestyle. Above she draws on the *final day* discourse to legitimise the current choices that previously would not have stuck with her. The effect of her self-description above is that the ‘new’ Marietjie is presented as a more spontaneous individual who is in control of her choices and takes responsibility for them. She also hints at the notion that the changes she has made are long-term ones, in that she defines them as a change in her “view on life”. This has a further empowering effect on Marietjie as she can attribute any positives changes to her new vision on life. Thus, the implication is that her new view on life would affect how she approaches every aspect of life.

It might be tempting to assume that Marietjie has fallen for the pleasures of secondary gain and the abdication of her responsibilities, but she states:

... I don’t want to be pitied. I have always been a strong person, and I
don’t want them [referring to her family] to pity me, or feel sorry for me.

Marietjie then reinforces her responsibilities with regard to her condition and the possibilities of affecting her own outcomes in life: “Yes, I don’t know whether I’m going to have it for the rest of my life, because the thing is anxiety can be overcome” and “But
the thing is that it is anxiety attacks and there is nothing that can make it better for you, except you yourself, or with time”.

**Conclusion**

It is important to note how Marietjie had utilised the various discourses that come into play in her family dynamics to adjust her perception of self after having had her first anxiety attack. Through the reflective process of our conversation, it came to light that Marietjie always defined her role as one of sacrifice; where her function as caregiver and helper to others became rigid and inflexible. Her comparison of her interpersonal role at present (i.e. allowing more time for herself) as compared to before her diagnosis, suggests a definite impression of change that she picked up on and framed as growth. It is also important to note that her recognition of her ‘growth’ occurred within a context of reflection and in response to questions that request her to attribute meanings to certain experiences. Therefore, the growth she recognised in herself is not necessarily an inherent effect of her being diagnosed with anxiety attacks, but was constructed in the process of searching for meanings of her experiences in a reflective exercise. In this sense, it can be said that I joined Marietjie in a collaborative effort to construct and negotiate the effects of anxiety disorder on her self-perception, and thereby in the construction of her identity.

Having presented the results of the three participants, the focus in Chapter 5 shifts to a discussion and integration of the results into various process themes. Thereafter, a
discussion of the strengths and limitations of this study is afforded and recommendations for further research in the field of diagnostic labelling are outlined.
Chapter 5 – Discussion and Conclusions

In the preceding chapters, a critical discussion of the various perspectives regarding the effects of diagnostic labels on individuals’ identities and sense of personal agency was offered. In Chapter 1, the aim of the study was framed as an exploration of diagnostically labelled individuals’ identity constructions as empowered individuals with the capacity for personal agency through the meanings derived from various social discourses, thereby reframing their diagnostic labels as interpersonal metaphors.

Chapter 2 focussed on the existing literature and theoretical conceptualisations of labelling, including social psychological explanations, labelling theory, systemic perspectives and social constructionist views. The epistemological foundations of the study were made explicit and arguments for the applicability of the social constructionist epistemology with its emphasis on narrative constructions of reality were presented.

In Chapter 3, the focus shifted to the methods of application of the research assumptions to address the aim of the study. The method of analysis, namely discourse analysis, required an explicit and critical consideration of my central role, as researcher, in shaping the narratives and hence the meanings that participants attach to their experiences. Attention was given to the effects of the questions I posed, the possibilities that are facilitated or restricted by these questions, as well as the subjective nature of the interpretive process when analysing participants’ data. Accordingly, my interpretations of participants’ results were offered in Chapter 4 and the collaborative nature of meaning-
making between researcher and participant was emphasised. Various discourses that underlie the meanings that participants derived from their experiences of adapting to their diagnostic labels were discussed in a narrative plot that illustrates the interaction among these discourses in the meaning-construction process.

Having briefly considered the foregoing chapters and the progression of focus each presents, this chapter will embodies an endeavour to integrate the results obtained from Chapter 4 and to offer a critical account thereof in light of the existing literature and theoretical perspectives, as well as the study’s research assumptions. This integrative discussion is guided by an effort to assess the success of the research endeavour to achieve the aim of the study, as proposed in Chapter 1. Accordingly, this chapter will concludes with a discussion of the strengths and limitations of the study and recommendations for future research in the field of diagnostic labelling.

**Integration of results**

Departing from the view that diagnostic labels hold implications that are inherently good or bad to those individuals who are diagnosed with it, this study was approached from a social constructionist epistemology. The adoption of a social constructionist epistemology held the implication that participants were viewed as active agents in the constructions of their identities in lieu of the meanings they derived from their experiences with these labels in relation to significant others. Accordingly, participants’ results were analysed for the interpersonal effects their diagnostic labels held for them.
Attention was also paid to the ways in which they constructed their identities by way of the meanings they derived from those interpersonal experiences that pertained to their diagnostic labels.

Apart from the subsequent effects of being diagnosed with a diagnostic label, the analyses of participants’ results also revealed that their personal, interpersonal and vocational expectations and goals prior to their diagnoses played an important mediating role in their identity constructions. This is because these expectations and goals invariably formed a basis for the meanings they derived from their experiences of adapting to their diagnostic labels. As such, participants presented their experiences of adapting to their diagnostic labels as significant learning curves, as they afforded them opportunities for reflecting on various aspects of their lives prior to their diagnoses. Through such reflection the recognition of the necessity of personal, interpersonal or occupational growth in these domains of life became paramount.

It seems that this reflective process that is facilitated, to some extent, by the diagnostic labels and interpersonal experiences surrounding it, allowed participants to compare their current functioning in specific domains of living to that prior to the diagnostic events. Consequently, through these reflecting and retrospective comparing processes the experience of personal growth was facilitated in participants. Furthermore, since the diagnostic labels were mostly framed as external or objectified conditions that afflict participants, they symbolise hindrances to participants’ adaptations. However, diagnostic labels as ‘hindrances’ combined with participants’ experiences of having achieved
growth in various domains of functioning, despite these hindrances, serve to bolster their identity constructions as empowered individuals and survivors of adverse conditions.

Following the latter argument, the diagnostic events as reflected in participants’ stories can be conceptualised as perturbations that served to provoke reflections and that challenged the existing organisations of participants’ systems of functioning (i.e. self as a system, self in system and system in context). This statement resonates with the second-order cybernetic conceptualisation of psychotherapy, where psychotherapeutic intervention is framed as an act aimed at disrupting the rigidified homeostatic organisation of the family system by targeting individual family members’ perceptions of their roles in relation to the family system. It is accepted that the client or family will naturally construct new patterns of organisation through the homeostatic disruption that is provoked by the therapist (Andolfi, 1983; Minuchin, Nichols & Lee, 2007).

The above discussion of the process of identity construction is grossly oversimplified, and it must again be emphasised that it relies on a complex interplay of the various meanings (as informed by various social discourses) participants derived from their experiences with their diagnostic labels. Nevertheless, although the participants’ experiences differed immensely as a function of their specific diagnoses, their personal histories, family structures and personalities, among other aspects, similarities were observed in the process of their identity constructions following the diagnostic events. Given that these similarities reflect process descriptions of participants’ stories rather
than content descriptions, they will heed process themes and will be discussed briefly below.

**Process Theme 1: Status quo**

It is evident in each participant’s story that the diagnostic event symbolises a watershed moment in the course of his or her life. In reflecting on their experiences with their respective diagnoses, all three participants expressed a form of counterfactual thinking where they fantasised about what course their lives could have taken had they not been diagnosed with their diagnostic labels. The latter points to the perception in all three participants of the existence of a status quo for their lives prior to the appropriation of the diagnostic labels. The status quo as such represents the patterns of behaving and relating to others that informed each the participants’ expectations of their futures.

Stefan, who, due to contextual factors and his young age, was unaware of his ‘underlying dyslexia’, describes the status quo of his life during school to have been one of disappointment, academic failure and punishment. Stefan’s awareness of dyslexia being the source of his struggles in school did not seem to drastically alter his perception of self or his expectations for the future. Rather, his diagnostic label served to amplify the injustices he experienced as a result of the status quo. Therefore, the possibility for Stefan himself to be construed as an agent of change and personal liberation is not only made possible, but the identity implications of such a construction of self as ‘revolutionary’ become more powerful.
On the other hand, Tiaan perceived himself to be a very active and healthy individual, whereas Marietjie conceptualised herself as a strong woman who was always ready to sacrifice her time to provide a helping hand to others. From Tiaan and Marietjie’s responses to the news of their diagnoses as well as their struggles to incorporate the perceived implications represented by their diagnostic labels into their existing perceptions of self, it follows that the status quo constituted a personal reality for each.

Thus, prior to the diagnostic event and the appropriation of their diagnostic labels, the reality of the status quo seemingly constituted the only course of life (with limited room for deviation) that was conceivable for the participants. The diagnostic event and the resulting appropriation of their diagnostic labels can therefore be conceptualised as disruptive events in as far as it disrupted the status quo of the participants, either through its negation or amplification.

**Process Theme 2: Disruptive input**

The process theme of disruptive input is put forward as a description of the disruptive effects the diagnostic events had on the participants’ expectations for their lives. Two of the participants, Tiaan and Marietjie, described the unsettling effects of experiencing the diagnostic event. Both also expressed a sense of confusion and uncertainty following the diagnostic event, which is strongly linked to a struggle of incorporating the diagnostic label into their existing definitions of self. The diagnostic event and the diagnostic label they received can therefore be likened to a systemic perturbation in as far as they contain
information that is seemingly irreconcilable with their current identities (which include their role expectations and patterns of relating to others).

The irreconcilable nature of the diagnostic label seems to be an important factor in setting in motion the reflective meaning-construction process, in that it contains the potential effect of inducing homeostatic disruption in the participants’ support systems. Accordingly, this disruptive input fosters the need for experimentation with new roles and patterns of interpersonal relations.

Although Stefan’s story contains the same process theme of ‘diagnostic label as disruptive input’, the age at which he was diagnosed, as well as the relative vagueness (to him at least) of the concept dyslexia seems to have altered the experience of disruption he went through. In other words, whereas Tiaan and Marietjie experienced a sudden confrontation with the paradoxical task of integrating their diagnostic labels into their existing identities, the disruptive effects of Stefan’s diagnostic label were more subtle and prolonged over time.

Furthermore, it is important to note that the interpersonal effects of Stefan’s diagnostic label commenced very early in his life, and he presents his struggles with dyslexia and his identity formation as a lifelong battle against oppression. As such, the disruption that the diagnostic label effected in Stefan’s life is different compared to that of Tiaan and Marietjie.
Firstly, the disruptive effects Stefan experienced did not resemble a crisis event, as in the case of Tiaan and Marietjie, but rather a subtle and gradual build-up to a climactic situation from which new interpersonal patterns could emerge. Also, different to Tiaan and Marietjie, the young age at which Stefan’s diagnostic label started affecting his life meant that it formed a crucial part in the development of his identity, whereas Tiaan and Marietjie were confronted abruptly with the task of adapting their identities.

Although differences emerged in the ways in which participants experienced the disruptive effects of the diagnostic event, it seemed to have the common effect of inducing a systemic crisis in the form of altering each participant’s perception of himself or herself in relation to others. These systemic crises then led to an alteration in the ways they relate to significant others.

**Process Theme 3: Ensuing crises and experimenting with new patterns**

The diagnostic labels of participants and the disruptive effects they present for the status quo (in terms of their perceptions of self, their role definitions in relation to others and their future expectations) resulted in either a blocking or an amplification (in the case of Stefan) of their usual patterns of relating to others. Such blocking and amplification of interactional patterns seem to have the effect of inducing what can be described as systemic crises in the participants’ lives. As such, the status quo as the sole construction of their personal realities is no longer a feasible frame through which the new input
regarding self in relation to others (as symbolised by their diagnostic labels) can be incorporated into their existing identity constructions.

This latter statement is illustrated through Tiaan and Marietjie’s admissions that, after the diagnostic events and their considerations of the implications their diagnostic labels signified, they were no longer able to carry on with their lives as usual. Both agreed that they were confronted with the task of restructuring their interpersonal relationships. Tiaan had to deal with the task of relinquishing control to others and sacrificing activities that he held dear, without losing his sense of purpose and personal worth. Marietjie, in a similar vein, was confronted with the task of laying down her helping duties and settling into the role of being the one who is taken care of.

Through his appropriation of his diagnostic label, Stefan seemed to experience an intensification of the status quo present in his life, in that the dyslexia label reinforced his role definitions as an academic ‘failure’ and thereby impeded others’ expectations of him to achieve success. This amplification of the status quo in Stefan’s life can be said to have elevated the difference in perceptions he and others had of him. This is because it provided a new element to the context in which his successes could be interpreted and also amplified. By having the label dyslexia, his perceived chances of attaining success decreased, and therefore the importance of the successes he did obtain was amplified. This also had the effect of altering his usual patterns of relating to others, and in effect of defining his identity in a different way.
In each participant’s story, the disruption of existing patterns of relating and the experimentation with new patterns seemed to play a crucial role in the process of constructing meaning in terms of his or her experiences with his or her diagnostic label.

**Process Theme 4: Constructing meaning**

The meaning-construction process described here seems to invariably depend on a juxtaposition of old versus new patterns of behaving and relating to others. This reflecting process seems to draw on the differences the participant is able to recognise between these older and newer patterns, and is thus punctuated and conceptualised as personal growth. The recognition of personal growth seems to rely heavily on the participants’ perceptions that their new patterns of relating represent an alteration to or improvement on their previous patterns of relating. This was illustrated in the stories of all three participants, an example of which is Marietjie’s admission that she is now more attentive to her own needs, whereas in the past she always placed her own needs second to those of others.

As the diagnostic labels with its perceived implications for participants’ lives represent a watershed moment between their old and new patterns of relating, these diagnostic labels are retrospectively conceptualised as having a mediating effect on participants’ perceived personal growth. In this sense, all three participants utilised their diagnostic labels as objectified realities with definite implications for their identity constructions and future
expectations. These objectified labels were then juxtaposed to their personal qualities and capacities for adapting to the ‘real implications’ of their diagnostic labels.

In this way then, for all three participants, their experiences of rising above the debilitating effects of their conditions by utilising their own personal qualities could be construed as occasions for personal growth.

**Researcher’s comments and reflections on the integrative process of reflection**

To ensure the stable growth of an individual’s relationship systems, the diagnostic input or label demands that the relational structure and organisation of the respective systems undergo changes in order to avoid entropy (disorganisation) and move toward a new balance or homeostasis. This, from a second-order cybernetic perspective, requires that individual changes in terms of individuals’ role definitions and their positioning in relation to others evolve to allow for the integration of the new information (Andolfi, 1989; Minuchin et al., 2007).

In order to enlarge the individual’s frame of reference to allow for a harmonic integration of the diagnostic label with his or her identity (i.e. perceptions of self in relation to others), the individual has to attribute meaning to the diagnostic label as an important factor that contributed to personal growth. Because identity is defined in interpersonal terms, the meaning attributed to the diagnostic label requires that it also be defined in
interpersonal terms or have interpersonal significance (in that the label informs alternative ways of relating to others).

Again, although this meaning-construction process is presented as following a linear path, this is deceiving, because the meanings that are attributed to the various experiences related to the diagnostic label do not precede or coincide with the actual experiential events, but are created after the fact through a self-reflective process. Therefore, the diagnostic event and the diagnostic label do not have fixed positive or negative meanings. Rather, their meanings are seen to wax and wane as a function of the individual’s reflection on the significance it has for his or her identity construction in relation to others.

As long as the diagnostic label is defined purely as an intra-psychic condition with no relevance to the individual’s interpersonal functioning or patterns, the experience of personal growth is unlikely to be recognised during self-reflection and the diagnostic label would at best serve a useless function – and at worst be attributed with debilitative meaning. As is illustrated in this study, if diagnostic labels can be redefined as interpersonal metaphors, i.e. as pertaining to the individual’s patterns of relating to others and as containing indications for alternative patterns of relating, these labels could be utilised to restore the individual’s sense of empowerment and thereby foster a positive perception of self.
Strengths and limitations of the study

This study represents an effort to describe and conceptualise from a social constructionist viewpoint how individuals utilise various social discourses in order to construct meaning from their experiences with being diagnosed with neurological, learning or psychiatric conditions.

The focus of the study was on the interpersonal effects of diagnostic labels and the way this impact on participants’ identity constructions in relation to others. In this sense the study has illustrated that, by reframing diagnostic labels as interpersonal metaphors, participants were able to construct meanings from their experiences with their diagnostic labels. This meaning-construction process occurs when the diagnostic labels are reframed as lenses through which participants can view their symptomatic behaviour as signals that disrupt old and rigid patterns and inform alternative patterns of relating to others.

I trust that this study contributes to a different understanding of diagnostic labelling and departs from the moralistic conceptualisations of diagnostic labelling as inherently good or bad. Given the fact that human beings rely on language to make sense of their experiences, it is a difficult, if not impossible, task to eliminate categorical devices such as diagnostic labels. This research offers a way for psychotherapists to conceptualise and utilise diagnostic labels as part of clients’ personal realities, rather than to ignore its relevance to clients’ spheres of experience.
Furthermore, this study highlights the importance of recognising the constructing powers of each individual to create meaning from his or her own experiences. Thus by respecting and appreciating clients’ internal frames of reference and offering, rather than imposing his or her own views on the nature of diagnostic labels, a psychotherapist can collaborate with the client in exploring ways to construct meanings from their diagnostic labels, rather than reiterating its debilitative nature.

Apart from its contributions as discussed above, this study contains several limitations that warrant consideration. Firstly, given that the research sample consisted of only three individuals, the results of this study cannot be taken to be representative of the general South African population. In addition, the individuals that participated in this study represent a fairly homogenous cultural segment of the population. As participants were all white, Afrikaans-speaking individuals, one cannot determine the degree to which an individual’s culture, ethnicity and language affects the meaning-construction processes involved in constructing their identities.

Secondly, since a purposive sampling strategy was employed in this study, the identification and selection of participants relied on selection criteria as determined by the aim of this study. This holds the implication that the sampling strategy was biased in that it excluded individuals who did not fit the selection criteria. As such, the possibility exists that the findings of this study do not apply to individuals who do not fit the selection criteria. It must be said, however, that, as mentioned in the introduction to this study, the aim was not to discover generalised truths, but rather to explore the ways in
which diagnostically labelled individuals manage to construct stories of success. Therefore, the sampling criteria (with its focus on individuals who have adapted to their diagnostic labels) reflect the aim of the study, namely ‘looking at individuals’ tapes of success’.

Thirdly, the final limitation I wish to discuss concerns the degree of my involvement in interpreting and shaping the participants’ stories. This points to a high degree of subjectivity with regard to the results of this study, which makes comparisons with results of other similar studies implausible. Although the purpose of this study was not to provide an objective account of the participants’ experiences, I trust that my attempts to account for my personal influence on the research results are reflected through all the chapters. Through this effort of transparency, I encourage the reader to scrutinise my interpretations and engage in his or her own interpretive effort in order to judge the trustworthiness of the research findings.

**Recommendations for future research on diagnostic labelling**

Having considered the strengths and limitations of this study, it is recommended that future research endeavours into the field of diagnostic labelling focus on applying similar methods to an expanded participant sample. Specifically, attention can be focussed on exploring the effects of culture, language and ethnicity on identity construction as mediated through diagnostic labels.
Given the existence of cultural differences in conceptualising the individual’s role in society (as reflected in individualistic versus collectivistic cultures), an interesting question would be how individuals from different cultural and ethnic backgrounds utilise social discourses to construct meanings from their experiences with diagnostic labels to inform their identity constructions in relation to others.

Since the social constructionist epistemology emphasises the role of language in the construction of social realities, the question emerges whether the language structures (including syntax and semantics), concepts and metaphors available to speakers of different languages affect the process of meaning construction presented in this study.

Finally, although the recommendations presented here encourage a comparison of results across cultural, ethnic and language domains, it must again be kept in mind that the purpose of this study was not to provide generalisations. As mentioned in Chapter 3, the social constructionist epistemology posits that social realities are subjective in nature and mediated by a process of social negotiation. In the spirit of this basic assumption, it is recommended that different researchers apply their own perspectives to similar explorations to enter in a dialogical process regarding the effects of diagnostic labels on identity constructions, and avoid the ideological pitfalls of strict generalisations as discussed earlier in this study.
Reference list


Appendix A: Interview schedule

This interview schedule is used as a guide to explore important areas of interest during the interview process. The questions are not followed rigidly, but act as markers to guide the researcher and participant as to the type of information that is sought and to prevent the interview from going too far off track.

1) Biographical Details
   - Age:
   - Level of education:
   - Occupation:
   - Relationship status:
   - Family structure (nuclear family, only child, siblings, divorced parents, etc.):
   - Home circumstances (who lives with participant?):
   - Diagnosis:

2) Particulars of Diagnosis
   - Can you remember when you were first diagnosed with (enter the participant’s condition)?
   - By whom were you diagnosed as such?
   - What led up to you visiting the Doctor, Psychologist, Psychiatrist, etc.?
   - Whose decision was it to seek help?
3) Perception of Self

- What was your reaction when you were diagnosed with (enter the participant’s condition)?
  i. How did you feel?
  ii. What did you think?
  iii. What did you do?

- If response is negative in focus: Was there anything that eased your thoughts, feelings, etc.

- What were you told about (enter the participant’s condition)?
  i. By the health practitioner?
  ii. By other people?

- What was your reaction to these people and what they said?
  i. How did you feel?
  ii. What did you think?
  iii. What did you do/say?

- Has your perception of yourself changed in any way following your diagnosis?
  i. If so, how?
  ii. If negative focus: can you think of any positive changes in your perception of self?

- How would you describe yourself
  i. before being diagnosed?
  ii. since being diagnosed?
- What was the hardest thing about being diagnosed with (enter the participant’s condition)?
- What was the best thing about being diagnosed with (enter the participant’s condition)?

4) Interpersonal Effects of Diagnosis

- What was your family’s response to your diagnosis?
- Was this response what you hoped for?
- Would you change anything about their response?
- How has your relationship with your family changed after the diagnosis?
  i. If negative focus: Do you recall any positive changes that occurred after the diagnosis?
- How do other people respond to your diagnosis?
  i. If negative focus: Are there people who respond differently, say more positive?
- How has your diagnosis affected your relationships with other people?
  i. If negative focus: Has your diagnosis had any positive effects on your relationships?
- Did/Do you tell other people about your diagnosis?
- If so, who did you tell and why?
- If not, what kept/keeps you from telling others?
- Is there anything that makes it easy to tell people?
- Is there anything that makes it difficult to tell people?
- Have you ever regretted telling anyone about your diagnosis?
  
  i. If so, how did this affect your future disclosures?
  
  ii. If negative focus: Did this interaction have any positive effects on your choice to disclose?

- From whom do you seek support/who is your provider of support?

- Would you say that you had/have sufficient support or would you (have) benefit(ed) from more support?

5) **Current Understanding of Condition**

- If the man on the street asked you to explain what (enter participant’s condition) is, how would you explain it to him?

- Would you say (enter the participant’s condition) makes you different from people who are not ‘mentally ill’?
  
  i. If so, in what way?
  
  ii. If negative focus: Any positives?

6) **Occupational (or Educational) Outcomes of Diagnosis**

- How has your diagnosis affected your outcomes at school or in your job?

- Would you say that you benefited in any way from your diagnosis?
  
  i. If so, in what way?

- Would you say that you have been disadvantaged through your diagnosis?
  
  i. If so, in what way?
7) Sense of Wellbeing

- How would you describe your sense of wellbeing or quality of life?
  (Specifier: for example, would you say that you are living a fulfilling life, do you find something lacking in life, are you unsatisfied with life, etc.?)

- How would you describe your level of functioning in life? (Would you say that you are in the process of adapting to living with (enter the participant’s condition), have adapted to living with it, are nowhere near adapted to living with it?)

- What adjectives would you use to describe yourself as a person living with (enter the participant’s condition)?
Appendix B: Consent form

Original Consent Form – Participant Copy

My name is Francois Nico van Zyl and I am registered as a Master’s student in Clinical Psychology at the University of South Africa (Unisa). As part of the Master’s course I am required to complete a research project. I am conducting research regarding individuals’ experiences of adapting to the stigma of being formally diagnosed with a psychiatric, neurological or learning condition and what they perceive their outcomes to be relative to their label. My hope is that this research may benefit each participant, though this cannot be guaranteed, and may be helpful to professionals and lay people who deal with similar clients.

The interview will be available to my dissertation supervisor and the examiner responsible for awarding a mark for my dissertation. No personally identifiable details will be used in the transcribed version of the interview; only general information so as to protect your anonymity.

Your name will not be recorded anywhere on the transcribed interview, and no one will be able to link it to you. All personal information will remain confidential.

The interview will last around 60 minutes. I would like you to be as open and honest as possible in answering the questions I pose to you. Some questions may be of a personal and/or sensitive nature. I will also ask some questions that you may not have thought about before, and which involve thinking about the past or the future. Even if you are not absolutely certain about the answers to these questions, try to think about them and answer as best you can. When it comes to answering these questions, there are no right or wrong answers.

Your participation in this research project is voluntary. If you do not wish to answer a question, you may refrain from doing so. Even if you agreed to participate initially, you may stop at a later stage and discontinue your participation. If you refuse to participate or withdraw at any stage, you will not be prejudiced in any way.

If I ask you a question that makes you feel sad or upset, we can stop the interview and discuss it. There are also people to whom I can refer you who are willing and able to talk it through with you if you so wish. If you need to speak with anyone at a later stage, a professional at the Unisa clinic can be reached at the following telephone number 012 429 8930.

I may require (an) additional interview/s at a later stage, and may also like to discuss my findings and proposals around the research with you, once I have completed my study.
If you have any other questions about my study, please feel free to contact my dissertation supervisor Prof. Juan Nel, at the University of South Africa, on:
012 429 8089 or via email: nelja@unisa.ac.za
Original Consent Form – Researcher Copy

I hereby agree to participate in the research regarding individuals’ experiences of adapting to the stigma of being formally diagnosed with a psychiatric condition and what they perceive their outcomes to be relative to their label. I understand that I am participating freely and voluntarily. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not prejudice me in any way.

The purpose of the study has been explained to me, and I understand what is expected of me.

I understand that this is a research project, which may or may not necessarily benefit me personally. I have received the telephone number of a person to contact should I need to speak about any issues that may arise as a result of this interview. I understand that this consent form will not be linked to the research documentation, and that my personal information will remain confidential. I understand that, if possible, feedback will be given to me on the findings of the completed research.

Signed at ________________, on this ________ day of _____________ 20___.

__________________________    _________________________
Name of Participant              Name of Researcher

__________________________    _________________________
Signature of participant           Signature of Researcher

Additional consent to audio and/or video recording:

In addition to the above, I hereby agree to the audio and/or video recording of this interview for the purposes of data capture. I understand that no personally identifying information or recording concerning me will be released in any form. I understand that these recordings will be kept securely in a locked environment and will be destroyed or erased once data capture and analysis are complete.

Signed at ________________, on this ________ day of _____________ 20___.

__________________________    _________________________
Name of Participant              Name of Researcher

__________________________    _________________________
Signature of participant           Signature of Researcher